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SOCIAL DISPARITIES AND CANCER-RELATED STRESS

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ABSTRACT

Socioeconomic disparities in health have been demonstrated over a wide range of health outcomes. A differential capacity to cope with stressful life events has been proposed as one mechanism contributing to disparities. SES differences in coping with cancer-related stressors are the subject of this thesis.

Study 1 examined SES differences in psychological distress associated with cancer screening. Lower SES groups had lower psychosocial wellbeing but were not more vulnerable to adverse psychological consequences. Study 2 tested the hypothesis that SES differences in adjustment to a cancer diagnosis are greater when the prognosis is poorer. There was some evidence that lower SES groups were more adversely affected by a more advanced disease stage diagnosis compared to higher SES groups. The qualitative interviews in Study 3 considered the possibility that this was due to differential experience of care, but found little evidence that cancer patients' experiences of medical care differed by SES. Studies 4, 5 and 6 used a large longitudinal sample of cancer patients (breast, prostate and colorectal). Study 4 explored whether SES moderated psychosocial adjustment related to the types of treatment received, presence of co-morbidity or disease stage at diagnosis. The effect of receiving surgery appeared to diminish rather than increase SES differences in adjustment. Study 5 showed that higher SES groups had more psychosocial resources to cope with a cancer diagnosis and that resources were related to psychosocial wellbeing, but despite this, Study 6 found no evidence that lower SES groups experienced poorer adjustment to a cancer diagnosis over time.

Overall the studies found little evidence that lower SES gives greater vulnerability to serious stressors, and if anything, suggested that a cancer

diagnosis seemed to minimise the expected SES differences in psychological wellbeing.

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CHAPTER 1

Socio-economic status and psychosocial responses to stress

Socio-economic status (SES) has been a major issue in the public health arena for many years. A strong relationship has been found between SES and health such that people with lower SES have consistently worse physical health outcomes than those with higher SES at every level of SES (Acheson 1998, Marmot & Wilkinson 2005, Marmot et al 1978). The association between SES and health is graded in that there is an incremental rise in good health from the bottom of the social spectrum to the top (Marmot 2004). The relationship is not restricted to physical health; people from lower SES backgrounds also experience poorer mental health than those from higher SES backgrounds (Adler et al 1999, Lorant et al 2003, Matheson & Summerfield 2001, Power et al 2002).

The mechanisms proposed to explain these inequalities in health outcomes variously include material, cultural-behavioural, psycho-social, life course and political influences (see Table 1) (Bartley 2004). The 'material' explanation suggests that differences in income affect purchasing power that determine, for example, quality of diet or housing, which have direct effects on health. People from different social backgrounds are also likely to share cultural norms that influence behaviours that in turn affect health. The higher prevalence of smoking amongst lower socio-economic groups (Department of Health 1998) is often cited in support of the cultural-behavioural explanation of inequalities in health. The psycho-social model proposes that differences in the work and social environment between SES groups may result in different levels of exposures to stress and impact on psychosocial resources such as control

and social support (Taylor & Seeman 1999). These differences in resources and exposure are thought to impact on bodily functions and subsequent physical and mental health. The life-course approach also seeks to incorporate how inequalities in health arise throughout life; how differences in childhood experiences and behaviour can predict adult trajectories in terms of occupation and social circumstances that lead to adult differences in morbidity and mortality (Kuh et al 2003). Finally, macro-social influences could also make a contribution to inequalities in health. For example, the availability of public health services, provision of good quality education to all social groups, and the standard and availability of public housing all have the potential to influence health outcomes. All of these diverse explanations are either argued to be, or have been shown to be, part of the process that causes inequalities in health.

Table 1 Explanations for the relationship of social inequality to health from Bartley (2004)

	Explanation type				
	Material	**Cultural/ behavioural**	**Psycho-social**	**Life course**	**Political economy**
Influences	Individual income determines diet, housing quality, polluted environment, dangerous work.	Differences in beliefs, norms and values mean that individual members of less advantaged social groups are less likely to drink alcohol moderately, abstain from smoking and take exercise in leisure time.	Status, control, social support at work or at home, balance between effort and reward influence health through their impact on body functions.	Events and processes starting before birth and during childhood may influence both physical health and the ability to maintain health. Health and social circumstances influence each other over time.	Political processes and distribution of power affect provision of services, quality of physical environment and social relationships.

The research in this thesis is concerned particularly with the psychosocial model and explores the effects of cancer-related stressors in relation to SES and psychosocial wellbeing using observational studies. The subject of the thesis is the relationships between SES, exposure to stress and psychosocial outcomes. To understand these relationships, this chapter will review the underlying processes and pathways involved in stress, specifically resources and stressors. The combination of higher stress exposures and poorer coping resources in lower SES groups have been proposed as a determinant of what is called 'allostatic load' (McEwen & Seeman 1999). This concept alludes to the overall wear and tear on the body which itself further compromises the individual's ability to cope with new stressors.

Transactional Model of Stress

This thesis focuses on psychological and social responses to stress rather than physiological processes and outcomes. Physiological models define stress in terms of a bodily response. Whilst important for understanding the effects of stress on biological systems, it largely ignores the function of different environments in provoking stress and any protective psychosocial factors that could contribute to individual differences in the stress response. Conversely, early psychological approaches to the assessment of stress concentrated on assessing stressful stimuli rather than responses. Within this approach, stress was measured using checklists of 'stressors' based around life events (e.g. divorce, moving house, illness, death of a relative). An individual's level of 'stress' was defined in terms of the number and type of life events experienced. The most widely known of these checklists is the Social Readjustment Rating Scale (Holmes & Rahe 1967) which lists 43 events, weighted for average

stressfulness on a scale of 1 to 100. The difficulties with this approach are that checklists can never be truly comprehensive, and different life events may have different meanings for different individuals, and consequently be experienced as more or less stressful.

Any psychosocial model of stress needs to take into account the fact that individuals react and adapt differently, both physiologically and psychologically, to the same potentially stressful experience. The cognitive theory developed by Lazarus and Folkman (1984) that has come to dominate the psychological literature on stress and coping, is a transactional model that addresses this issue. The theory defines stress in terms of a dynamic interaction between the person and the environment. In order for a person to experience stress in any given situation they must first realise that there is something harmful or threatening occurring. This process is termed 'cognitive appraisal': "The process of categorising an encounter, and its various facets, with respect to its significance for well-being" (Lazarus & Folkman 1984)(Chapter 2, p.31). Cognitive appraisal is further divided into two types: primary and secondary appraisal. A primary appraisal of stress requires that the individual's goals or assumptions are challenged in some way. If the event is appraised as stressful, it is further understood to be an event of harm/loss (damage has already been sustained), threat (an anticipated harm or loss) or challenge (an adverse event that has opportunities for mastery or gain) (Lazarus 1999). These three appraisals of harm, threat and challenge can co-occur in many situations. For example, in the case of a cancer diagnosis, some harm has already occurred, a person may perceive some further future threat in terms of progression or recurrence of the disease, and also feel challenged to control themselves or their own emotions within the difficult situation.

The type of appraisal that the person makes also depends on available resources. Secondary appraisal is the cognitive-evaluative process of focussing on what can be done once a primary appraisal of threat, harm or challenge is recognised. It involves an evaluation of available resources and coping options. Resources refer to a wide range of factors from demographic variables, such as age, gender and SES, through to personality traits such as optimism and mastery and other social factors such as social support. There is some evidence that resources influence appraisal and choice of coping strategy. The role of dispositional optimism particularly has been examined in a number of studies (Carver et al 1993, Schou et al 2004, Stanton and Snider). For example, Stanton and Snider (1993) studied a group of 147 women who had been referred for a breast biopsy. After biopsy 36 patients received a cancer diagnosis. Higher distress prior to receiving biopsy results was predicted by being younger and being less optimistic. People with low dispositional optimism were also more likely to use cognitive avoidance as a coping strategy and this resulted in greater negative affect. This finding illustrates the idea that personal resources, such as optimism, can have both a direct effect on distress as well as an indirect effect via choice of coping strategy as proposed by the stress/coping model.

Secondary appraisal is also an evaluation of what coping options are actually available and the likelihood that a given strategy will be successful in ameliorating the stress and that the strategy can be carried out effectively (Folkman & Greer 2000, Lazarus & Folkman 1984). Folkman and Greer (2000) define coping as: "The thoughts and behaviours a person uses to regulate distress (emotion-focused coping), manage the problem causing distress (problem-focused coping) and maintain positive well-being (meaning-based

coping)" (p.12). Within their model, coping is conceived as a process. Other research has focussed on coping as a more stable personality style or trait (Burgess et al 1988, e.g. Ong et al 1999). The trait approach tends to over-simplify and does not give due reference to characteristics of the situation that may influence the choice of coping strategy.

The choice of coping strategy needs to be appropriate to the situation because there are no 'good' or 'bad coping strategies per se. However, during more stressful situations more or less collective patterns of coping may be observed, although there will still be some individual variability within this and different people may also have tendencies to use certain strategies over different times and places (Lazarus 1999). Looking at the literature on coping strategies in people with a cancer diagnosis illustrates these points. Studies in cancer patients variously find that the use of fighting spirit (Schnoll et al 1998), humour and acceptance (Carver et al 1993), seeking social support, focusing on the positive and distancing (Dunkel-Schetter et al 1992) are beneficial in terms of psychological wellbeing. The use of denial, emotional venting or cognitive avoidance is related to increased distress (Carver et al 1993, Deimling et al 2005, Dunkel-Schetter et al 1992, Hack & Degner 2004). The studies do not always agree on which strategies are beneficial and which lead to heightened distress. For example Carver et al (1993) report that acceptance predicts lower distress whereas Hack and Degner (2004) report that acceptance is related to increased distress. These disagreements may arise because of a lack of conceptual clarity concerning each coping strategy (e.g. acceptance as facing reality versus acceptance as resignation), reflected in the many different measurement strategies used in coping research. Additionally the differences between samples in terms of type of disease, disease stage, types of treatment

and time since diagnosis add to the situational variability making direct comparisons less valid. The lack of uniformity may therefore indirectly support the tenets of the Lazarus and Folkman model (1984) which emphasises the situational nature of coping. Because of the nature of coping it is not possible to say simply which coping strategies will be advantageous.

At the core of this transactional model is the idea of a balance between resources and demands. A novel situation such as attending cancer screening, receiving a cancer diagnosis or undergoing treatment for cancer represents an increase in demands. This could tip the balance so that demands outstrip resources, and stress is experienced. An inadequate coping response could then result in negative emotional states (Lazarus 1999). Coping strategies are initiated to change the stressful situation with further iterative appraisal and coping responses being carried out until the situation is resolved.

One of the difficulties with the model is that both appraisals and coping are inherently difficult to assess. Appraisals and reappraisals are thought to occur continually. As appraisal is conceived as part of a dynamic process, it is hard to distinguish between the appraisal and the stress response. Also, although the appraisal process may at times be fully conscious and deliberative, there is also the potential for appraisals to happen at a more subconscious level with appraisals happening rapidly within short periods of time (Lazarus 1999). These issues make accurate assessment of appraisals difficult to pin down. The idea of 'coping strategies' is also very broad making them difficult to assess comprehensively. Two examples of generic coping measures which are currently widely used are the Ways of Coping Checklist (Folkman & Lazarus 1985) and the COPE (Carver et al 1989). Both measure different specific strategies, which suggest that neither is inclusive in its measurement of coping.

Another issue is that the model is exclusively within the psychological domain and does not include consideration of physical interactions. However, the model clearly moves forward the idea of individual differences in the stress process and provides an appropriate framework for the studies in this thesis that explore socio-economic differences in psychosocial responses to stress using observational studies.

SES and Psychosocial Resources

The discussion of the stress/coping model highlighted the importance of psychosocial resources in adaptation to stress. Although the research studies of this thesis focus on psychosocial outcomes such as depression and quality of life, psychosocial resources including perceived control, optimism and social support, are also important in the stress-health pathway (Taylor & Seeman 1999). If lower SES groups have fewer resources to draw on during times of stress, this could result in a less effective coping response and in turn, to poorer outcomes such as greater distress. Below I review the evidence that health and SES are related to perceived control, optimism and social support. Other resources, for example, self-esteem or neuroticism, may also be important in the relationship between SES and health, but they are not included in the research studies of this thesis.

Control

Personal control, also termed 'mastery', has been defined as 'the extent to which one regards one's life-chances as being under one's own control in contrast to being fatalistically ruled' (Pearlin & Schooler 1978) (p 5). Perceptions of personal control relate to better health outcomes across a range

of illnesses and psychological outcomes. For example, a greater sense of control is associated with a reduced risk of coronary heart disease (Marmot et al 1997), better recovery from heart and lung transplants (De Vito et al 2003) and better self-reported physical health status (Caputo 2003). Reduced symptoms of depression and anxiety are also related to an increased perception of control (Griffin et al 2002). Penninx et al (1998) explored the effect of personal control in chronically ill people (diabetes, lung disease, cardiac disease, arthritis and cancer). Perceptions of control were related to fewer symptoms of depression both in the chronically ill and in the healthy comparison subjects. The effects for high control were stronger in the chronically ill participants, possibly indicating a buffer effect. Increased control has also been shown to relate to decreased distress in cancer patients (e.g.Thompson et al 1993).

The mechanisms by which personal control influences physical and psychological outcomes are unclear. Personal control may relate to the use of more effective coping strategies, such as decision-making, active planning for the future, and information-seeking, whereas low perceived control may lead to an inability to take decisions or make changes resulting in a feeling of helplessness and increased stress and distress. However, this hypothesis is often an assumption within the literature rather than a proposition that has been tested extensively. Hobfoll et al (1994) report an association between more prosocial, action coping strategies and a greater sense of mastery and between antisocial and passive strategies and lower mastery in a sample of students and community residents. Active coping strategies also related to lower emotional distress in this sample. Similarly Burgess et al (1988) studied control and coping styles in newly diagnosed breast cancer and lymphoma patients. They found that people with the belief that they had control over the important

outcomes in their lives used more positive and confronting coping styles and also reported less anxiety and depression than people with low perceptions of control.

There is some evidence that perceived control can affect physiological reactivity, thus implying a route to physical health outcomes. For example, Steptoe et al (2003a) examined elevations in plasma fibrinogen as one of the pathways through which low control at work could increase cardiovascular disease risk. The study was conducted with 221 men and women drawn from the Whitehall II cohort. Plasma fibrinogen was assessed at baseline, immediately after performance of acute stress tasks (colour-word and mirror tracing), and 45 minutes later. Men experiencing low job control had greater fibrinogen responses to acute stress than did those with high job control. This provided some evidence that low job control could influence cardiovascular disease risk partly through provoking greater fibrinogen stress responses.

Conversely, there is also evidence from the literature on physiological reactivity to stressful conditions that suggests that the beneficial effects of high perceived control could be reversed in situations where there is an incongruity between perceptions of control and the opportunity to exert actual control. Strong mastery beliefs may promote unrealistic expectations for control resulting in patterns of physiological arousal that promote the development of atherosclerosis. For example, Sieber et al (1992) studied changes in natural killer cell (NK) activity in men after exposure to controllable or uncontrollable stress (noise). Men who perceived they had control over the noise showed no reduction in NK activity. On the other hand, the subjects who perceived that they had no control over the stressor did show reduced NK activity immediately after the first 20-minute stress session and up to 72 hours later. The belief in

control enhanced the negative impact of stress on NK activity. This suggests that people who use high control strategies in situations that are inherently unchangeable could lead to adverse outcomes. Other research has also revealed that there are occasions when actual behavioural control (as opposed to perceptions of control) can be disadvantageous. Eitel et al (1995) report that patients with end stage renal disease who had control over their treatment (self-administered treatment) had poorer psychosocial adjustment than those who had no control over their treatment (hospital administered treatment). They suggest that, in patients who are severely ill, the burden of control becomes too great. Both of these studies highlight the possibility that there are occasions when the largely beneficial value of control beliefs can be negated.

In terms of the social distribution of personal control, there is clear evidence from the Whitehall II study that control at work makes a significant contribution to the socio-economic gradient in coronary heart disease incidence (Marmot et al 1997). Those in lower occupational grades report lower job control in terms of decision authority and skill discretion and this lack of control has an impact on physical health. Another important study by Lachman and Weaver (Lachman & Weaver 1998) examined social class differences in sense of control using a survey method in three national probability samples of men and women aged 25-75 years (N1 = 1,014; N2 = 1,195; N3 = 3,485). Participants with lower income had lower perceived mastery, as well as poorer health. Higher perceived mastery was related to better health, greater life satisfaction, and fewer depressive symptoms. Hierarchical multiple regression analyses were used to explore interactions between control beliefs and income on health outcomes. Importantly, control beliefs worked as a moderator in these relationships so that low SES participants who had a high sense of

mastery showed levels of health and wellbeing comparable to the higher SES groups. However, this was a cross-sectional study and so it was unclear whether health outcomes influence control and income rather than vice versa. There was also some evidence of social class bias in the responders to the survey, and lower income groups were under-represented in the samples.

Another recent study by Pudrovska et al (2005) using a sample of 1,167 older adults (65+ years) also suggests a moderating effect of mastery on the psychological effects of economic hardship. The authors report an association between economic hardship in later life and increased levels of depression and anxiety in people who had low levels of mastery. In people with high mastery there was no association between hardship and either depression or anxiety. Again this was a cross-sectional survey, leaving questions of causality unanswered, but these results lend further support to the findings of Lachman and Weaver (1998) and the possible role of perceptions of control in the association between SES and psychological wellbeing.

The evidence suggests that personal control could act as a coping resource in times of serious stress and may be an important factor in how people from different social backgrounds adapt to novel stressors.

Optimism

Optimism has often been defined as a relatively stable personality trait under the term 'dispositional optimism'. This is a person's general expectation that good outcomes will occur in most circumstances. The most influential researchers in this field have been Charles Carver and Michael Scheier who developed the Life Orientation Test (LOT) (Scheier et al 1994) as a measure of dispositional optimism. They have carried out a number of studies that explore

the relationship between optimism and health (Carver et al 1993, Scheier et al 1986, e.g. Scheier et al 1999). The factor structure of the LOT suggests that there could be two separate factors, one for positively worded items and one for negatively worded items (Scheier et al 1994), which have often been used to construct two subscales that are viewed as measuring optimism and pessimism respectively.

Optimism is related to engagement in health and social behaviours (Carver et al 2003, Robbins et al 1991, Steptoe et al 1994). Studies show that optimism is related to a wide range of health-promoting behaviours such as improved dietary practices, low-alcohol consumption and non-smoking (Robbins et al 1991, Steptoe et al 1994). One study has reported that optimism in heart patients is associated with improved diet and increased levels of exercise within a cardiac rehabilitation programme (Shepperd et al 1996). Carver et al (2003) have also explored disruption of social and recreational activities in a longitudinal study of breast cancer patients. They showed that pessimism related to increased social and recreational disruption up to a year after surgery for breast cancer. This area of research seems to indicate that optimists are more likely to engage in activities to ameliorate the effects of ill health whereas pessimists are more likely to withdraw.

Research that has focussed on the impact of optimism on physical health report mixed results. Some studies report better physical outcomes for optimists such as decreased mortality in head and neck cancer patients (Allison et al 2003) and higher natural killer cell cytotoxicity in HIV+ women (Byrnes et al 1998). Other studies report no association between physical health and optimism (e.g. Schofield et al 2004, Tomakowsky et al 2001). Segerstrom's review (2005) of the effect of optimism on immune response during exposure to

stressors concludes that optimism does have an effect on immune response, but that this effect is not always beneficial. She argues that optimists always engage with a stressor, regardless of whether the stressor can be easily overcome or ameliorated. Her research studies have examined the effects of optimism and pessimism on immune response (delayed-type hypersensitivity [DTH] skin testing with mumps and candida antigens: larger DTH responses indicated stronger cellular immunity) in law students living away at college or at home (Segerstrom 2001). The results have shown that in situations where a stressor can be engaged with and resolved, optimists have a beneficial immune response, whereas in the situation of an uncontrollable stressor, pessimists have the beneficial immune response because they disengage from the task. These relationships are illustrate in Figure 1. These results indicate that the engagement strategies of optimists may be detrimental, at least in the short-term but the long-term effect of optimists' engagement strategies have not been explored. It is possible that the beneficial effect of pessimistic disengagement,.

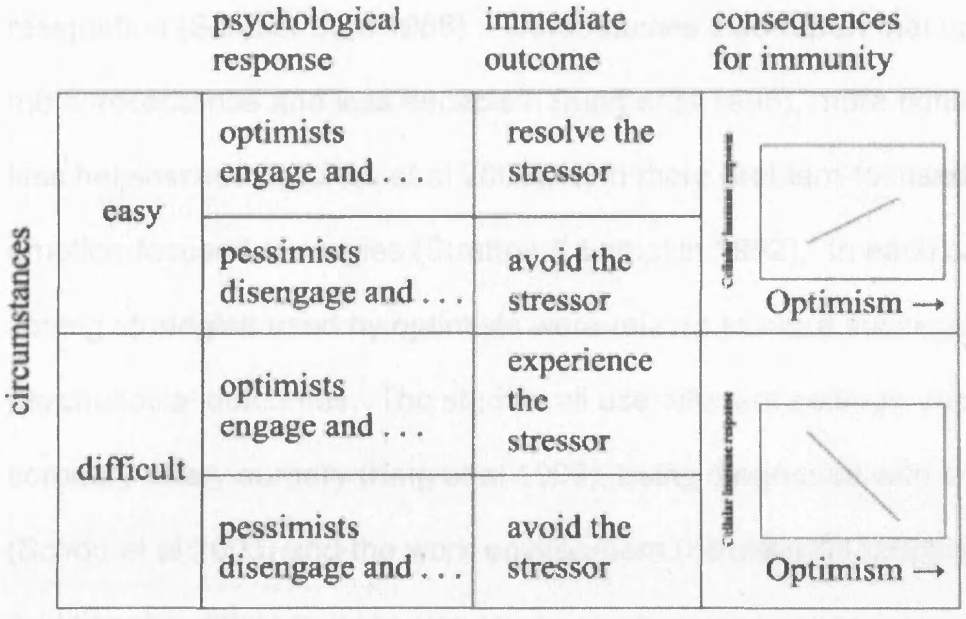


Figure 1 Effects of optimistic engagement and pessimistic disengagement when circumstances are easy or difficult. Effects on immunity shown are drawn from effects on delayed-type hypersensitivity (DTH) induration in studies of first-year law students (Segerstrom 2005) .

at least in terms of immune response, could be short-lived. The complex relationship between optimism and immune response possibly explains why associations between optimism and physical health outcomes are inconsistent The relationship between optimism and psychological adjustment is much more uniform. Optimists appear to experience less distress during stressful events, even events as extreme as a cancer diagnosis (Carver et al 1993, Epping-Jordan et al 1999, e.g. Schou et al 2004, Stanton & Snider 1993).

This may be because optimists, by definition, are those that expect and focus on positive outcomes, meaning that they are inherently more cheerful, but it has also been argued that optimists use different coping strategies to manage the stressful situation (Carver et al 1993). In particular, optimists tend to use more problem-focused coping strategies and, when this is not appropriate (e.g. when the situation is appraised as uncontrollable), turn to emotional coping strategies, that are effective in the particular situation, such as acceptance and resignation (Scheier et al 1986) . Other studies also report that optimists use more acceptance and less escapism (King et al 1998), more fighting spirit and less helplessness (Schou et al 2005), and more problem-focused and less emotion-focused strategies (Strutton & Lumpkin 1992). In each case, the coping strategies used by optimists were related to more successful psychosocial outcomes. The studies all use different settings: recovery from coronary artery surgery (King et al 1998), being diagnosed with breast cancer (Schou et al 2005) and the work environment (Strutton & Lumpkin 1992). Additionally, different measures of coping strategies, comprising various specific strategies, are often used across studies. The assorted situations themselves may make different types of coping strategy more or less appropriate, in terms

of their effectiveness, and the different measures of coping used in each study make comparisons between studies difficult. However, it does appear that the use of particular coping strategies is one way in which optimism is related to better psychosocial wellbeing.

The relationship of optimism to SES has not been fully explored. Taylor and Seeman (1999) report associations between SES and optimism, using the LOT in four unpublished datasets (recovery from a hurricane, recovery from coronary artery bypass and women at risk for HIV and the natural history of HIV in gay men) in their review of psychosocial resources and the SES-health relationship. They used the LOT in the format of two subscales, one for optimism and one for pessimism. They describe that the relationship with SES is most prominent for pessimism rather than optimism: higher SES people expected fewer negative outcomes than those with lower SES, but the relationship between the expectation of *positive* outcomes and SES was not as strong. I have recently worked with colleagues on an analysis of data from two community samples of older adults in England (N =5,099) and Scotland (N = 10,560) that found a strong gradient in optimism across SES groups (Robb et al 2005) (Appendix I). When negatively and positively worded items were analyzed separately, the gradient remained significant in both cases, although the effect was slightly stronger for the negatively worded items. Lower SES people seem to view the future as containing fewer positive and more negative events. This evidence implies that optimism has a role to play in successful adaptation to stressful situations and its possible relationship to SES is worth further exploration.

Social Support

Social resources are both objective states (e.g. social networks - counting a person's number of social ties) and subjective experiences (e.g. self-reported perceptions of available emotional and instrumental social support from family and friends) (McNally & Newman 1999). Studies that examine social support find stronger relationships with physical health and well-being outcomes for perceived support rather than received support (e.g. Wethington & Kessler 1986). Although social support may have direct effects on health by changing health behaviour (e.g. shared common behaviour between members of a social network) or by giving people confidence and perceptions of control over the environment (Stansfeld 1999), perceived social support also appears to act as a coping resource during times of stress. For example, high levels of support are related to increases in quality of life and fewer symptoms of depression and anxiety in cancer patients (Alferi et al 2001, Hann et al 2002, Parker et al 2003). An important finding by Reynolds and Perrin (Reynolds & Perrin 2004) is that the nature of giving and receiving social support needs to be appropriate to the situation. They found in a sample of 79 breast-cancer patients that, where support was given, but was unwanted by the patient, it could lead to poor psychosocial adjustment. High levels of social support may be particularly important for women and younger cancer patients in terms of their psychosocial adjustment (Hann et al 2002).

Another protective social resource, closely related to social support, is the ability to communicate within the family. This may be of particular importance during times of stress. For example, when an individual is diagnosed with cancer, family members may have their own fears and concerns about cancer that prevents them from being able to talk about the illness and

cancer patients may not want to discuss the problems they are experiencing because it will upset or worry their family. If families are able to talk openly about the illness there are increased opportunities for information exchange and the provision of appropriate social support resulting in the patient's better psychosocial wellbeing (Figueiredo et al 2004, Mesters et al 1997).

Social support also appears to be graded by SES: people from lower socio-economic backgrounds mobilise less social support during times of need (Mickelson & Kubzansky 2003, Taylor & Seeman 1999). Turner and Marino's (1994) study of 1,394 adults aged 18-55 years in Canada found an association between higher occupational status and higher levels of perceived social support. Regression models showed that a small, but significant proportion (15%) of the variation in depressive symptoms by SES was explained by levels of social support. A review of this area by Stansfeld concludes that there is stronger evidence for poorer social networks per se than for poorer quality of social relationships in low SES groups (Stansfeld 1999).

However, a more recent study by Mickelson and Kubzansky (2003) using data from the National Comorbidity Survey in the US (N=8,098), found that higher education and income were related to more perceived emotional support and fewer negative social interactions. They also reported that low SES groups experienced greater numbers of chronic and acute life events. Life events mediated the relationship between social support and SES. Mediation was assessed by looking at changes variance associated with SES when the life events variables were included in regression and structural equation models. They concluded that low SES groups were unable to mobilise support because they experienced multiple acute and chronic stressors that led to an erosion of available support. This could be because low SES people require support from

other individuals from the same socio-economic background. These people are therefore experiencing their own chronic and acute stressors and cannot always provide extra help to others. This is consistent with the idea that differential exposure to multiple stressors experienced by different SES groups can impact available psychosocial resources that are required to meet novel stressors (Gallo & Matthews 2003). However, caution needs to be employed when assessing the conclusions of this study because a cross-sectional method was used, this meant that the causal directions of these relationships could not be confirmed and arguably testing of mediational models in the absence of longitudinal data is somewhat limited (Cole & Maxwell 2003).

Summary

This brief review indicates that psychosocial resources are required to secure good physical and mental health but they may vary by SES. The evidence is not always definitive and still lacking in some areas, particularly as regards research into the relationship between optimism and SES. Further research still needs to be done to explore these relationships.

SES and Exposure to Chronic Stress

Chronic stress happens either when the stressor occurs repeatedly or continuously, or because the stressor is of a nature that cannot be overcome or adapted to (Baum et al 1999). Differential exposure to chronic stress may come from work (Marmot et al 1997) or home (Feldman & Steptoe 2004) environments as well as through the differential occurrence of adverse life events (Mickelson & Kubzansky 2003, Stronks et al 1998). These chronic stressors are also associated with a number of physical and psychological health outcomes (Marmot et al 1997, Stansfeld et al 1999).

Many background or ambient stressors are embedded into people's living or working conditions. There is greater over-crowding, crime and noise pollution in lower SES areas (Ellaway & Macintyre 1998). These are all socio-ecological stressors. Feldman and Steptoe (2004) explored the distribution of various aspects of neighbourhood strains in relation to SES and their effects on physical functioning in a sample of 658 adults. These included social cohesion and control, neighbourhood problems (e.g. litter, noise) and neighbourhood vigilance (how much the individual felt that they had to be alert or defensive in their area). Lower SES was related to increased experiences of neighbourhood strain and this strain was in turn associated with poorer physical functioning. Similarly there is now a large body of work from the Whitehall II study which has demonstrated that lower SES is associated with greater work stress (such as low control at work and high job demands) that relate to increased risk for physical health problems, such as cardiovascular disease (Marmot et al 1997) and psychological problems, such as depressive symptoms (Stansfeld et al 2003).

Lower SES is also associated with experiencing a greater number of adverse life events, both acute and chronic e.g. divorce, illness in the family, financial difficulties, being subjected to violence or crime and death of a loved one (Mickelson & Kubzansky 2003). For example, Stronks et al (1998) report that lower educational achievement was related to higher exposure to stressors including life events (e.g. moving house, divorce, change in employment) on top of long-term difficulties (e.g. financial problems, poor neighbourhood conditions) using a Dutch sample of adults (age 17-74, N = 2,559). This higher exposure to stressors was related to an increased risk of perceived health problems. There was also a difference in perceived health problems by level of education, such

that those with less education reported more problems. They estimated that between 10 and 15% of the difference in perceived health problems according to educational level was accounted for by the differential exposure to stressors. Logistic regression models using cross-sectional data were used to estimate this effect and so the causal direction of these associations could not be confirmed.

Another study by Turner et al (1995) also explored exposure to both chronic stressors and life events in relation to SES (indexed by occupation) and depression in a sample of 1,393 adults aged 18 to 55 years. Their results lend support to the findings of Stronks et al (1998). Again, Turner et al (1995) report that lower SES is related to increased stress exposure and also increased depressive symptoms. Differences in total stress exposure (chronic and life events) accounted for 38 per cent of the effect of occupational class on depressive symptoms. Regression models indicated that chronic stress may play a stronger role in explaining SES differences in levels of depression compared to life events.

One proposed mechanism for how exposure to chronic stress can impact on physical health is 'allostatic load'. Allostasis refers to the ability of the body to maintain stability through change. It denotes the ability to respond to stress by activating adaptive physical systems that lead to behavioural or psychological responses that ameliorate the threat. These physical systems return to their resting states once the threat is dealt with. Adaptive physiological responses to stress include increases in blood pressure to enable physical and mental exertion, and activation of adrenal steroids to encourage food intake or brain activity. However, continual, or over activation, of these systems can also be harmful to health by inducing, for example, atherosclerosis

or immunosuppression. Inappropriate or over-activation of these systems is referred to as 'allostatic load'. McEwen and Seeman (1999) refer to four types of allostatic load: i) 'repeated hits' where there is continual system activation because of exposure to multiple stressors; ii) 'lack of adaptation' where there is a failure to habituate or adapt to a stressor and the individual does not return to 'normal' or 'resting' functioning; iii) 'prolonged response' where there is a slower than normal return to pre-stress functioning; and iv) 'inadequate response' where the stress system is not sufficiently activated resulting in other maladaptive compensatory activity. These four types of allostatic load demonstrate the different ways in which the physiological stress systems can become impaired over time.

Differences in biological reactions to stress that support the concept of 'allostatic load' are found in a number of studies that also demonstrate how 'load' is socially distributed by SES. Work stress has been associated with higher ambulatory blood pressures and higher cortisol responses among people from lower SES backgrounds (Landsbergis et al 2003, Pickering 1999, Steptoe et al 2003b). In the Whitehall II study people from the lower occupational grades had larger cortisol awakening responses than those in higher occupational grades (Kunz-Ebrecht et al 2004), suggesting that low SES groups experience low level, sustained psychobiological activation.

SES and Psychosocial Response to New Stressors

If people from lower SES backgrounds are exposed to more chronic stressors, their relatively fewer psychosocial and material resources may be highly taxed on a day-to-day basis. This could lead to psychological vulnerability in response to new stressors such as an illness, because they have

no reserve capacity to deal with a new threat. One description of impaired ability to respond adequately to novel stressors has been put forward by Taylor and is referred to as 'reactive responding' (Taylor 1998). She proposes that the lack of resources and exposure to chronic stress associated with lower SES will limit the development of effective self-regulatory strategies that are required to respond to novel stressors. Instead, lower SES groups develop a more limited set of psychological responses termed 'reactive responding'; a concept characterized by a state of chronic vigilance, a lack of options, a lack of opportunity for learning and skill development, short-term goals and an emotionally charged response. This concept has not yet been effectively tested in any systematic research but describes a possible mechanism by which lower SES groups may fail to respond adequately to novel stressors.

Another psychological model proposed by Gallo and Matthews (2003), which they refer to as the 'reserve capacity framework' is shown in Figure 1.2. They hypothesise that lower SES environments relate to greater exposure to stress which results in more negative and less positive emotion. The greater stress exposure also leads to greater use, and consequently depletion of, psychosocial resources that are required to buffer the effects of novel stressors. This combination of exposure and resource depletion can result in an impaired psychological response to novel stressors including greater distress, as a direct result of inadequate resources, but also greater emotional reactivity i.e. an inappropriate or over-emotionally charged response to novel threats. They go further in suggesting that this poor psychological response can influence behavioural and physiological factors that result in poor physical health.

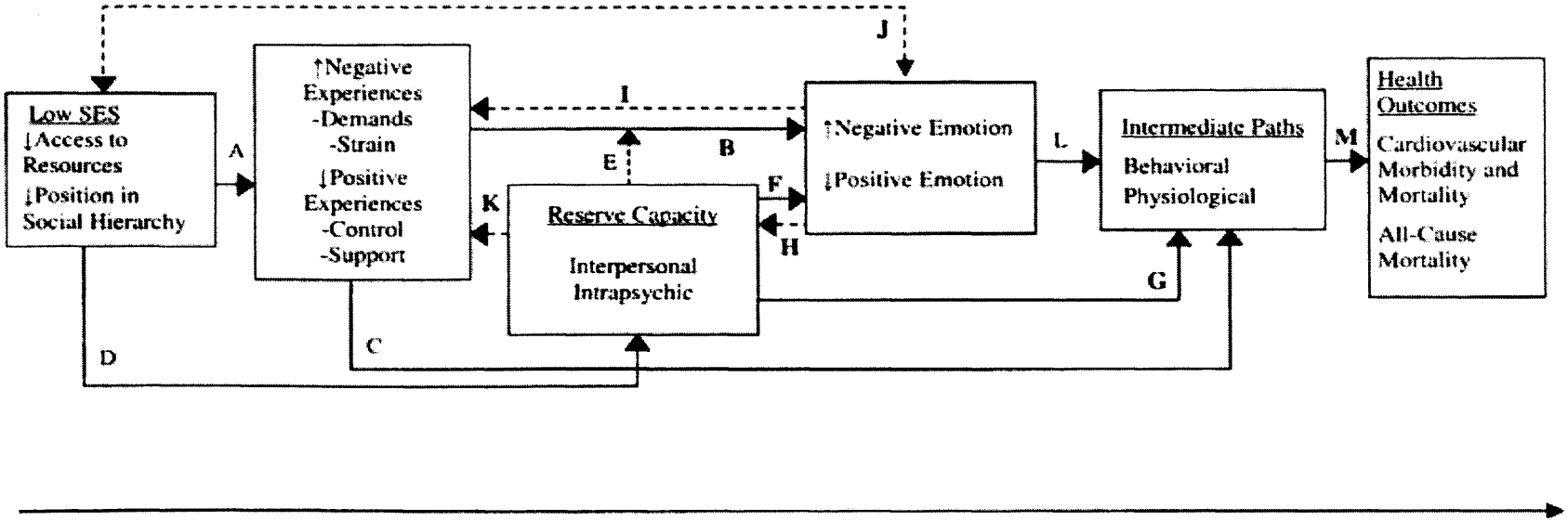
A recent test of this model used ecological momentary assessment (EMA) (a form of continual diary monitoring) over a two-day period in 108

women to explore the associations between stress, resources and affect (Gallo et al 2005). Lower SES participants experienced more exposure to stress over the two days. Low SES was also associated with less positive affect, although there were no differences between the SES groups in levels of negative affect. This was surprising given that the majority of research findings indicate an association between SES and psychological distress. Regardless of this issue, the analyses, using hierarchical linear modeling, did show that exposure to stress contributed to the association between SES and positive affect.

Lower SES participants also reported fewer psychosocial resources (e.g. mastery, optimism, self-esteem) that were measured using validated questionnaires. Deficits in these resources predicted increased stress experiences and poorer psychological well-being. These results support the idea that low SES is associated with increased stress exposure and depleted psychosocial resources which can lead to poorer psychological well-being.

The tests of emotional vulnerability were inconclusive and contrary to expectations. Women with lower SES, despite reporting lower positive affect overall, reported disproportionate increases in positive affect in response to stimulating or positive experiences over the two-day period. The authors suggest that this may reflect the rarity of positive events. There were no differences in negative affect responses to any types of event or in emotional responses (positive or negative) to stressful experiences. A limitation of this study was that the women were a self-selected group who responded to flyers, adverts or e-mail requests. The sample size was small (N = 108) altogether, but the recruitment method also resulted in a SES bias in participants resulting in a particularly small low SES group (N = 18/108). This obviously affected the ability to carry out rigorous statistical tests.

Figure 2 The reserve capacity model by Gallo and Matthews (2005)



"Arrow A shows the direct influence of SES on positive and negative psychosocial experiences. Arrow B indicates the direct impact of positive and negative experiences on positive and negative emotion. Arrow C shows the effects of stress on intermediate pathways to health outcomes. Arrow D shows that socioeconomic contexts affect the nature of the reserve capacity. Arrow E (dashed line) shows that the reserve capacity represents a potential moderator of the association between psychosocial experiences and emotions. Arrow F shows the direct link between reserve capacity resources and emotions. Arrow G shows that resources also affect intermediate pathways. Arrows H and I (dashed lines) indicate the possible reverse influence of emotional factors on reserve capacity resources and positive and negative psychosocial experiences, respectively. Arrow J (dashed, bidirectional line) shows that SES may have a residual influence on emotions that is not explained by psychosocial experiences or resources, and that emotional factors may also have a reverse influence on SES. Arrow K (dashed line) shows the direct link between reserve capacity resources and psychosocial experiences. Arrows L and M show that emotional factors may affect health outcomes through physiological and behavioral factors." Gallo and Matthews (2005) p.38

Another larger (N = 1,031) study that examined daily stressors reports some conflicting findings. Grzywacz et al (2004) explored differential exposures and vulnerability to stress in relation to SES using data from a subsample of participants within the nationally representative Survey of Midlife Development in the United States. Participants (aged 25-74) were interviewed on the telephone on eight consecutive evenings. Unlike the Gallo et al (2005) study where lower SES (indexed by education) was associated with increased exposure to stress, in this sample higher SES participants reported more exposure to stressors, but lower SES participants reported greater severity of stressors. Grzywacz et al also report that low SES was associated with increased negative affect (positive affect was not assessed) that was not found in the study by Gallo et al. This suggests that the findings of Gallo et al in relation to negative affect may have been anomalous. In terms of vulnerability to stressors, hierarchical linear modeling showed that nearly half of the educational differences in negative affect could be attributed to increased vulnerability amongst the least educated i.e. people with less than a high school degree were more reactive to stressors. This apparently strong association was not found for negative affect in the Gallo et al study. Similarly Turner et al's (Turner et al 1995) study of exposure to chronic stress, as opposed to daily stressors, discussed earlier, looked at interactions between SES and stress exposure and found no support for the vulnerability hypothesis. These studies produce somewhat conflicting and contradictory results suggesting that further research in the area of SES differences in response to novel stressors is needed to clarify the issues.

In summary, it is not clear whether greater exposure to adversity is sufficient explanation for the higher rates of ill health in lower SES groups, or whether differential reactions to comparable levels of adversity, as a consequence of limited psychosocial resources for dealing with them, make a contribution. One way of investigating this issue is to assess emotional and physical responses in different SES groups to the same potentially stressful situation.

Relatively few studies have explored the hypothesis that SES differentially affects psychological reactions to novel stressors. The exceptions to this are a number of studies of severe trauma. Lower SES appears to be a risk factor for developing post-traumatic stress disorder (PTSD) (Brewin et al 1999), with evidence coming from responses to a variety of traumatic situations including assault (Acierno et al 1999), air disaster (Epstein et al 1998) and treatment for breast cancer (Cordova et al 1995). Symptoms of PTSD include re-experiencing of the traumatic event (e.g. recurrent thoughts or images), avoidance of stimuli associated with the trauma, numbing of general responsiveness, a sense of a foreshortened future, and symptoms of increased arousal (e.g. irritability or outbursts of anger, difficulty concentrating). These symptoms cause significant amounts of psychological distress and often impair social or occupational functioning. Epstein et al (Epstein et al 1998) prospectively studied the development of PTSD in 355 health workers who aided victims involved in an air disaster (with assessments at 6, 12 and 18 months post-disaster). People who developed PTSD had less education (below university degree), were exposed to more burn victims, and experienced more stressful life events in the six months after

the disaster. This suggests that the resources, characteristics of the actual situation (i.e. differential exposure to burn victims) and chronic stress all contributed to the development of PTSD in this sample.

Other studies are needed to replicate these results and explore how SES interacts with characteristics of novel stressful situations to influence psychological outcomes. Future research could also examine a wider range of stressors, from less to more severe, and more diverse psychological processes and outcomes. Psychological reactions to serious physical illnesses, such as cancer, could provide a useful framework to explore this topic because all new patients will experience similar threats to their psychological wellbeing. Inequalities in health and health-care remain an important public-health issue, but the way in which SES impacts psychological responses to medical encounters has not yet been fully researched. The aim of this thesis is to explore the relationships between SES, cancer-related stressors and psychological wellbeing. The next chapter will describe the range of cancer-related stressors and their impact on psychosocial wellbeing.

CHAPTER 2

Cancer-related stressors and Psychosocial Outcomes

Cancer-related Stressors

There are a number of events on the pathway to a cancer diagnosis which have the potential to challenge individuals. These range from the milder stress of going for cancer screening through the greater challenge of other diagnostic tests, to the trauma of a cancer diagnosis, treatment and long-term survival.

Cancer screening

Screening programmes have been examined in detail in terms of evaluating the psychological impact of attending for diagnostic tests because of concerns that any psychological harm should be factored into assessments of costs and benefits of the national screening programmes. Cancer screening is potentially stressful due to the possible detection of a grave disease and because the screening tests are often uncomfortable (Wardle et al 2005, Wardle & Pope 1992). Increased psychological distress is related to a number of screening outcomes such as receiving an abnormal result that indicates a cancerous or pre-cancerous condition (McCaffery et al 2004, Steggles et al 1998, Wardle et al 1995), receiving false-positive results (Barton et al 2004), or having to re-attend for tests where inadequate procedures were used at the original screening (French et al 2004). Distress is also associated with uncertainty during the time period that people wait between receiving abnormal results and appointments for further investigations and treatment (Essink-Bot et al 1998, Parker et al 2002). The majority of studies report that the higher levels

of distress and anxiety among those receiving abnormal results decreases within a relatively short period of time, although some longer-term adverse consequences have been identified among women recalled for further investigations after mammography screening (Brett et al 1998, Olsson et al 1999).

The usual assumption is that the screening experience causes distress in those with abnormal or inconclusive results, but some suggest that the differential levels of distress seen in people with abnormal outcomes is due to relief experienced in those with normal results rather than increased distress in those with abnormal results (Cantor et al 2002, Essink-Bot et al 1998). Scaf-Klomp et al (1997) compared women who had false-positive mammogram results with women who had a negative screening result and an unscreened reference group. They found that although women who received a false-positive result showed greater psychological dysfunction 8-10 weeks post-screening compared to women with negative mammograms, the levels of dysfunction reported did not differ from the unscreened group. Women with normal mammograms showed the lowest psychological dysfunction scores both 8-10 weeks and 6 months post-screening. The majority of women who had received a false-positive result reported experiencing it as a stressful event, but it appears that the event is not so stressful as to heighten their psychological dysfunction. This gives some support to the idea that differences in psychological functioning are as likely due to feelings of relief in the negative group than to raised anxiety and distress in the false positive group. Other studies have found similar results. For example, a large scale trial of prostate cancer screening measured anxiety three weeks before screening, in the waiting room, and 1 week after the test. Participants' anxiety reduced when

they received a negative result compared to when they were waiting for the test. In the men requiring biopsies, scores were also taken during the two week wait for the result and 1 week after receiving a negative outcome. These men were the most anxious whilst they were waiting for their results compared to their scores one week after receiving the negative biopsy (Essink-Bot et al 1998). Similar work looking at referral for colonoscopy following a positive FOBT found that anxiety was highest after notification of a positive FOBT and before investigation by colonoscopy. In participants who had a negative colonoscopy (i.e. an original false-positive result) anxiety scores fell the day after colonoscopy and remained low 1 month later (Parker et al 2002). Negative results may lead to short-term decreases in distress making it appear that abnormal results increase distress and the false conclusion that screening is stressful.

The impact of the threat from screening, either in terms of increased distress or relief, could differ depending on individual characteristics and resources, but there is little research in this area. The majority of screening studies have focused on cervical or breast cancer screening as these are the most well established programmes. This has meant that there is only a small amount of data on men's reactions to screening and very few studies that are able to compare male and female reactions. Low SES individuals are known to be less likely to attend for screening (McCaffery et al 2002). However, there is no research which explores how SES may affect psychological reactions to the screening process itself.

Cancer diagnosis

The psychological impact of receiving a cancer diagnosis depends on a number of factors including disease characteristics (site of the disease, severity of the disease), communication about the disease, and the individual's situation and coping styles. The British government's commitment, as set out in the Cancer Plan (Department of Health 2000), to cut the time from receiving a diagnosis to receiving treatment to only 1 month, has meant that cancer patients must quickly comprehend information about their illness and then experience radical treatment over a relatively short period of time. Patients have more psychological difficulties around the time of diagnosis than later in the course of their illness (Burgess et al 2005, Norton et al 2004, Schroevers et al 2003, Steginga et al 2004). Being diagnosed with cancer affects multiple psychosocial outcomes in addition to psychological distress. Cancer can have an impact on relationships with family and friends (Northouse et al 2000) and consequently on the levels of social support the person receives during their illness (Reynolds & Perrin 2004). New relationships with medical staff have to be formed and the quality of these relationships is likely to be a significant factor in coping with the disease (Ong et al 2000). Cancer and its treatments can also impose a range of physical and functional disabilities which will increase the number of social problems encountered, from the ability to work with ensuing financial difficulties, to problems maintaining independence and the ability to care for oneself (Wright et al 2002).

Disease site

Cancer patients are not, of course, a homogeneous group in terms of the cancers they have and so for this reason alone there are likely to be differences in the levels of distress experienced by patients. Zabora et al (2001) studied

5000 cancer patients, of whom 58% had received a diagnosis within the last 90 days. The highest prevalence of distress was found in lung cancer patients, where 43.4% of the sample showed high levels of distress. Patients with brain, liver, pancreatic and head and neck cancer experienced similarly high levels of distress. Significantly lower levels of distress were experienced in patients with gynaecological, breast, colon and prostate cancers. This may be because of the better prognosis for these cancer sites. For example, the five-year survival rate for breast cancer in the 1996 to 1999 period was 77% compared to only 3% for women with pancreatic cancer or 12% for men with brain cancer over the same period (Cancer Research UK Cancer Statistics 2005). Other studies report similar findings, for example, Stommel et al (2004) found higher levels of depression in lung cancer patients compared to breast, colon or prostate patients in their sample of 860 older (65 years+) patients.

There may also be site-specific psychological issues. Female cancers, such as breast cancer, may raise issues related to body image, sexuality and feminity (Kunkel & Chen 2003). Similar issues surrounding masculinity may face men who present with testicular or prostate cancer as they confront possible fertility and sexual function limitations (Gurevich et al 2004, Moore & Estey 1999). Other cancers, such as bowel cancer, can be sources of embarrassment because of the detailed discussions of bodily functions, invasive testing procedures and possible long-term loss of bowel control (Rozmovits & Ziebland 2004).

In terms of the relationships between socio-economic status and cancer incidence and mortality, these also differ by disease site. Cancers of the lung, cervix and larynx show a strong positive gradient in both incidence and mortality, such that the most deprived groups have the highest incidence and

mortality. For lung cancer, the relationship is such that the lowest SES groups have a rate of incidence and mortality at around twice those of the highest SES. For other cancer sites, such as the colon, rectum, myeloma and uterus there is practically no relationship between SES and either incidence or mortality (Coleman et al 1999, Quinn et al 2001). Cancers of the brain, breast, and prostate, show a slight gradient in incidence, such that the highest SES groups have higher incidence, yet there is no gradient in mortality. This is because the highest SES groups have better survival rates (Coleman et al 1999). The causal explanation for the relationship between SES and cancer will include both site specific causal factors (such as the relationship between smoking in low SES groups and lung cancer) as well as more general factors across sites.

The research studies in this thesis focus on breast, prostate and colorectal cancer patients. These patients are likely to experience overall lower levels of distress than some of the other cancer sites, as discussed. These sites were chosen because they are all relatively common cancers that are both mixed-gender and gender specific. Additionally the relationship between SES and incidence in these sites is either non-existent or slightly negative (i.e. higher incidence in higher SES) meaning that any SES vulnerabilities in psychosocial adjustment will not be confounded by a greater overall cancer burden amongst the lower SES groups.

Disease stage

Disease stage at diagnosis is one factor that may affect psychological adjustment. Being diagnosed with more advanced disease implies a poorer prognosis that could be expected to pose a greater threat to psychological well-being. A number of studies show that more advanced disease is associated with poorer psychological well-being (e.g. (Gallagher et al 2002, Osborne et al

2003, Shimozuma et al 1999)) although other studies find little or no relationship between stage and psychological outcomes (Bleiker et al 2000, Kissane et al 2004, Norum 1997). One problem with these latter studies was either not including patients in the most advanced disease stage (e.g. (Bleiker et al 2000)) or making a comparison between early and advanced stage patients in widely different time frames since diagnosis (e.g. (Kissane et al 2004)). The majority of studies examining disease stage and psychological outcomes are with breast cancer patients and the findings may not be applicable to other types of cancer where disease stages may have subtly different meanings. There are few studies that examine this issue in colorectal cancer patients. One study did not find any difference between patients with Dukes B and Dukes C diagnoses in terms of psychological distress (Norum 1997). However, this study had a small sample size (n = 64) and did not distinguish between C1 and C2 diagnoses. There is a need to explore this issue further. These varied responses may also reflect the fact that patients are often poor at understanding the precise implication of their diagnosis (Chow et al 2001, Gattellari et al 1999, Quirt et al 1997, Weeks et al 1998).

Cancer treatment

Due to the nature of the treatments that are commonly available for cancer (e.g. surgery, chemotherapy, radiotherapy and hormone therapy), patients often find that treatment has a major impact on their everyday lifestyle, self-perception, physical abilities and psychological well-being. For asymptomatic patients, being treated for cancer may be the first time that they feel physically ill and are confronted directly by problems associated with having the illness. Patients are often asked to participate in treatment decision making

processes and the majority of patients also express a desire to do so (Bruera et al 2002) but this can be a difficult experience involving collating and understanding complex information and feeling responsible for making the right choices.

Some cancer treatments are also associated with increased levels of depression. Immunotherapeutic agents, such as interferon-alpha and interleukin, used to treat some cancers (e.g. kidney, melanoma), induce depressed mood as a direct side-effect (Capuron et al 2001, Musselman et al 2001, Paterson et al 2005). Other more extreme treatments such as bone-marrow or stem-cell transplants appear to result in higher levels of distress than cancers with other treatment modalities indirectly because of the more severe trauma to the body and isolation of the patient (Holzner et al 2004, Illescas-Rico et al 2002, Neitzert et al 1998).

More widespread treatments such as chemotherapy, radiotherapy or surgery commonly cause symptoms of illness including fatigue, pain and sickness. These symptoms experienced at chronic levels are debilitating and are connected to psychological distress (Bennett et al 2004, Hopwood & Stephens 2000, Portenoy et al 1994, Stommel et al 2004). The studies cited here find that different treatments can increase levels of distress. Patients currently undergoing treatment may differ in terms of distress compared to those who have completed or who are still awaiting treatment. After surgery, patients can be severely physically debilitated and experience a range of side-effects or novel complications such as lymphodema, impaired sexual functioning and incontinence, or having a colostomy, as well as psychosocial problems such as body image, family functioning and adjusting to new social roles. Chemotherapy is an on-going treatment with well known side effects

such as nausea and loss of hair that can produce similar psychosocial problems (Carelle et al 2002). Apart from these obvious side-effects chemotherapy is also associated with longer term cognitive dysfunction (Ahles & Saykin 2002). Radiotherapy is another long term treatment requiring considerable time commitment and also causing a number of side effects (e.g. chronic fatigue) which can have an impact on a person's ability to function at levels equivalent to pre-treatment (Tavio et al 2002). Chemotherapy and radiotherapy both prolong the length of time patients feel physically ill and also consequently prolong the length of disruptions to their normal life.

Hormone therapy is often used in the treatment of endocrine sensitive cancers including many cancers of the breast and prostate. Up to 70% of all breast cancers are hormone-sensitive and there are a number of hormonal therapies for both pre- and post-menopausal women with early or advanced disease. Hormonal treatments can have adverse side-effects such as vaginal dryness and hot flushes. But there is some evidence to suggest that patients prefer hormonal treatments over chemotherapy when there is a choice to be made (Fallowfield et al 2004). Women cite the avoidance of hair-loss, the convenience of the treatment (i.e. less disruption to everyday life) and an overall perception of fewer side-effects as the reasons for preference of hormonal therapy (Fallowfield et al 2004). This illustrates the value placed on quality of life during treatment.

There are also other studies which conclude that type of treatment, or other disease-related variables are not associated with distress (e.g. Burgess et al 2005, Norum 1997, Stommel et al 2004)). Burgess et al's (Burgess et al 2005) study of depression and anxiety in 222 women with breast cancer concludes that risk factors such as younger age, past-history of depression and

lack of social support, are more important risk factors for depression than cancer-related variables. These variables are risk-factors for depression in general population samples.

Although there is little research that has examined the impact of SES in relation to different treatments, one recent cross-sectional study using a sample of breast cancer patients (N = 1,357) (Janz et al 2005) does report on the interaction between education and treatment modalities. Receiving chemotherapy was associated with lower quality of life for all patients, but had a disproportionately worse impact on women with lower levels of education. The study shows that the impact of treatments may vary depending on patients' socio-economic backgrounds. Clearly these results not to be confirmed in further studies, and it would also be useful to explore if this type of effect could also occur when comparing those with different prognoses, disease sites or time since diagnosis.

Cancer and co-morbidity

Cancer incidence increases with age and consequently many people will be already be diagnosed with co-morbid conditions prior to their cancer diagnosis. As might be expected, the presence of a co-morbid illness in addition to a cancer diagnosis can have long-term adverse effects in terms of health status and disability that are not experienced by cancer patients without co-morbid problems (Hewitt et al 2003). Research in this area is surprisingly sparse but some studies do report that co-morbidity in cancer patients can predict increased depressive symptoms (Kurtz et al 2002) and poorer quality of life (Sarna et al 2005). Kurtz et al (2002) studied 158 older (65+ years) colorectal cancer patients. 60% of the sample had two or more co-morbid

conditions, indicating that this is a widespread problem. Patients with co-morbid illness reported more depressive symptoms across four waves of assessment. This suggests that co-morbidity may be an important factor in understanding psychosocial adjustment in cancer patients.

One study that examined co-morbidity in relation to SES in a mixed-sample of cancer patients (breast, lung, colorectal, prostate, stomach) found an association between lower SES and increased co-morbidity, particularly for heart or vascular disease (Schrijvers et al 1997). This is perhaps unsurprising given the higher rates of ill health amongst lower SES groups in general. The authors of this study suggested that some of the SES differences in the survival of cancer patients may be due to the presence of co-morbid illness but did not examine this hypothesis systematically. As there appears to be a relationship between co-morbidity and wellbeing, the increased levels of co-morbidity amongst low SES groups could also impact on psychosocial adjustment.

Cancer and survivorship

The term 'cancer survivor' has multiple meanings (Twombly 2004). Here the term refers to people who are cured of their disease or in remission and are no longer undergoing any treatment. The increase in incidence and survival from cancer, together with an overall aging population and an increase in population size, means that the term 'cancer survivor' applies to an increasing number of people. A number of issues related to having had cancer continue to affect 'survivors' despite their disease free status. Having had cancer can cause an increase in long-term health limitations compared to people who have never had cancer for more than a decade (Yabroff et al 2004). Long-term side effects of treatment include, for example, restricted arm movement and early

menopause in breast cancer patients (Ernst et al 2002, Hoda et al 2003) and loss of fertility in testicular cancer patients (Huyghe et al 2004) . Cancer survivors often continue to express anxiety related to disease recurrence (Mehta et al 2003, Thomas et al 1997b). Survivors frequently continue to attend outpatient clinics many years after the doctor has recommended discharge, in order to receive reassurance about their disease free status (Thomas et al 1997a). Having had a cancer diagnosis can seriously affect a person's social identity and role through loss of employment or change in status within the family (Zebrack 2000). Receiving a cancer diagnosis can represent a key social transition or change in a person's expected life trajectory leading to a process of long-term reorganisation and a search for meaning in the illness experience (Utley 1999). Appraisals of the meaning of the cancer experience can change over time and may not be evident until a long time after treatment is completed. Cancer is often appraised as an extremely stressful experience during the diagnosis and treatment phase. This appraisal may change to either an irrelevant or neutral experience in the years after treatment has been completed (Bowman et al 2003). Alternatively, many survivors come to appraise their experience as one that is positively trained e.g. in terms of an opportunity for personal growth (Manne et al 2004).

Cancer and Psychological Outcomes[1]

Thus far, this chapter has focussed on describing situational factors related to cancer that could effect psychosocial wellbeing. The next section will explore in more detail the psychosocial outcomes associated with having

[1] A version of this was published in *Depression and Physical Illness* Steptoe, A (ed), Cambridge University Press, a copy of the chapter is included in Appendix II.

received a cancer diagnosis that are explored within the research studies of this thesis.

The importance of psychosocial care for cancer patients rises in prominence as the number of people surviving cancer increases. Coleman et al (1999) report the overall 5-year survival rate for all cancer cases during the 1986-1990 period as 31% in men and 43% in women. This represents a dramatic increase in survival compared to the rates for the 1971-1975 which were 19% in men and 31% in women. This increase in survival is due to detection of cancer at an early stage leading to improved prognoses (Stockton et al 1997). There have also been improvements in the effectiveness of the treatments for cancer (McArdle & Hole 2002). As a result of this lengthened life expectancy, greater attention is now being paid to quality of life and psychosocial care for cancer patients. In the short term, psychosocial care means ensuring that patients maintain a decent quality of life during the diagnostic and treatment phase. In the longer term, the aims are to ensure that any lasting psychological problems are prevented so that the cancer patient can rehabilitate and return to 'normal' life.

The word 'cancer' is linked with fears about illness, dying and death in many people's minds. McMenamin et al (2005) assessed knowledge and awareness of breast cancer in a large general population survey (N = 2,355) and found that 66% of women overestimate their risk of developing breast cancer and 56% underestimated 5-year survival rates. Women believe that they are more likely to get cancer and that they will die from it than is actually the case. Other types of cancer also inspire this fearful response, for example, 70% of people taking part in a survey of attitudes to bowel cancer screening admitted that the thought of bowel cancer scared them (McCaffery et al 2003).

Not surprisingly, a diagnosis of cancer can lead to raised levels of psychological distress.

Prevalence of depression and anxiety

Estimates vary as to the number of people with cancer who will develop symptoms of anxiety (2%-25%) (Stark & House 2000) or depression (20%-50%) (Bottomley 1998, McDaniel et al 1995), depending on the definition of cases and the types of measurement used. Taking the prevalence of depression as an example, Massie's (2004) review of papers published up to 2002 cites a range of 0-38% for major depression and 0-58% for depression spectrum disorders (including more mild and moderate symptom reporting of depression. In studies published since 2002 this variability is still common. At the lower end, one study of a breast cancer waiting-room sample found that 29% of patients were in the distressed range. Follow-up interviews found that approximately 9% met criteria for major depression, 7% met criteria for minor depression, and 6% met criteria for generalised anxiety disorder (Coyne et al 2004). This is consistent with other recent estimates (Harter et al 2001, Kissane et al 1998, Sharpe et al 2004). At the higher end, Burgess et al (2005) reported that 48% of breast cancer patients experienced "clinically significant" depression or anxiety in the first year after diagnosis. However, this figure grouped individuals meeting full diagnostic criteria for major depressive disorder and generalized anxiety disorders with "borderline" cases of depression and anxiety. Burgess and colleagues note that a year after diagnosis, the prevalence of "clinically significant" depression and anxiety was only 15%, and thereafter the risk of anxiety and depression was no greater than in the general population, suggesting that the depression and anxiety being discussed is largely self-

limiting and not an enduring clinical disorder.

There are a number of factors which contribute to the wide variation in reporting of depression and anxiety in cancer patients. Levels of anxiety and depression are likely to vary according to the length of time that has elapsed since diagnosis (Burgess et al 2005). Higher estimates may also reflect use of symptom reporting recorded with the use of self-report questionnaires rather than diagnostic interviews (Hotopf et al 2002). Higher frequencies may also be seen in in-patients who have more severe symptoms or advanced stages of disease (Lynch 1995).

Given that there is little agreement over the prevalence of depression and anxiety in cancer patients, it is hard to compare prevalence rates with those of the general population or other medical patient groups. In UK older adults (60-74) (the group most likely to experience a cancer diagnosis) the 1-month prevalence is 7% for mixed anxiety and depressive disorder, 3% for general anxiety disorder and 1% for depressive episodes (Evans O et al 2003). Using a broader definition of depression and a wider age range, 10% of all adults (16-74) in the UK experience important symptoms of depression (also 1-month) (Singleton N et al 2001). In the US, Kessler et al (Kessler et al 2003) find 16.6% lifetime prevalence of depression and 6.6% 12-month prevalence. Some studies of the prevalence of depression and anxiety in cancer patient samples report comparable or lower levels to these, suggesting that there are no excess distress disorders in these patients. This idea was systematically assessed in a meta-analysis of 58 studies comparing levels of anxiety and depression in cancer patients to the general population. This showed that levels of depression were higher in cancer patients than in the general population but levels of anxiety and general psychological distress were not (van't Spijker et al

1997). Other reviews also conclude that depression is more common in cancer patients than among the general population (Hotopf et al 2002, Pirl 2004, Raison & Miller 2003).

Another useful comparison to place cancer patients in context is in relation to levels of depression and anxiety in other patient groups. Rates in patients with neurological disorders appear to be more consistently higher (30-50%) than in those with cancer or other medical illnesses (Massie 2004). Results from a recent longitudinal study of depressive symptoms in a sample of 8387 adults (aged 51 to 61 years) report that cancer patients have more depressive symptoms than those with hypertension, arthritis, heart disease, diabetes or stroke in the first two years after diagnosis. Levels of depressive symptoms in cancer patients were comparable to levels found in those with chronic lung disease (Polsky et al 2005). However, estimates of the prevalence of major depressive disorder among cancer patients, based on semi-structured diagnostic interviews with representative samples, overlap with the 5% to 13% range found in primary care patients (Barrett et al 1988, Coyne 1994, Katon 1987, Kessler et al 1985, Schulberg et al 1987). The best estimates of the prevalence of depression and anxiety in cancer patients suggest that the disorder is more common than in the general population, but perhaps only as common as, or little more common than, general medical patients, including primary care patients.

Measurement issues

Research studies involving cancer patients continues to use a wide range of self-report measures from a simple distress thermometer (Jacobsen et al, 2005) to the full range of longer standardized measures developed in other populations, such as the Center for Epidemologic Studies- Depression Scale

(CES-D; Radloff, 1977) and Brief Symptom Inventory (Derogatis & Melisaratos, 1983). Concerns that self-reported distress among cancer patients is confounded with cancer symptoms (such as fatigue, loss of appetite and cognitive impairment) have also led to interest in developing measures that are cleansed of somatic complaints. The most notable self-report instrument in this category is the widely used Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith 1983). The HADS excludes insomnia, anergia and fatigue, as well as symptoms of more severe psychiatric disorder.

Self-report measures are valid as general measures of distress, as measures of severity of depression or anxiety among patients who have a clinical diagnosis of depression or anxiety, or as a first stage screening of patients for follow up with a diagnostic interview to determine if they are actually depressed. In research studies, self-report measures are often used to compare groups who have more or less distress rather than identifying psychiatric 'cases'. This avoids the problem of using cut-off scores on self-report measures that must always strike a balance between sensitivity and specificity. I will be using self-report measures of distress to compare differences between groups and not for the purpose of identifying 'cases'.

Quality of life

A cancer diagnosis also has the potential to impact on psychological wellbeing in a wider sense including social, physical and functional abilities as well as emotional wellbeing. There is a large literature which looks at these broader quality of life concerns in cancer patients. There are two main research survey systems that measure quality-of-life in cancer patients: European Organisation for Research and Treatment for Cancer – Quality of Life

Questionnaire (EORTC-QLQC30) (Aaronson et al 1993) and Functional Assessment of Cancer Therapy – General (FACT-G) (Cella et al 1993). Both systems comprise a core questionnaire with cancer specific subscales that can be varied according to the patient group.

A number of studies have examined levels of quality of life in cancer patients and compare it to population controls. Studies using the EORTC scale show that cancer patients have worse quality of life compared to population controls (Hjermstad et al 1998), particularly in areas of social functioning, physical symptoms (such as fatigue and appetite loss) and financial difficulties (Hjermstad et al 1999). These effects are evident up to a year after diagnosis (Arndt et al 2004b, Arndt et al 2004a) but there is evidence that many domains return to normal or remain equivalent to population controls throughout the illness (Kopp et al 2004). Data using the FACT-G is not as extensive and there are some mixed results. Two studies found little or no differences between quality-of-life scores in cancer patients compared to general population samples (Holzner et al 2004, Miller et al 2002) and one study showed that cancer patients had lower scores (i.e. worse quality of life) (Cella et al 2003). Finding small differences between cancer patients and controls could be due to response shift in patients or that the outcome for most patients is generally good. Importantly the studies finding only small differences do show that type of cancer or treatment type can affect quality-of-life scores with bone marrow transplant patients having lower scores than either other patients or controls in one study (Holzner et al 2004) and ovarian patients having the lowest scores in the other study (Miller et al 2002). The controls in one study were inadequate as they were people attending for cervical screening and who may be experiencing some stress as a result (Miller et al 2002). Both the EORTC and

FACT scales were designed for use with cancer patients and comparisons with general population samples could be misleading for this reason. It seems likely that, as with levels of anxiety and depression, some cancer patients will be more adversely affected than others and a proportion of patients will have considerably lower quality of life compared to that of healthy populations.

At first glance, the content of the core modules of the EORTC-QLQC30 and the FACT-G appear similar. Both measures have physical, social and emotional subscales. However, systematic and statistical evaluations of their content reveal poor agreement. Kemmler et al (1999) compared responses on the two measures in a sample of 244 breast cancer and Hodgkin's disease patients. They found that only the physical domains were satisfactorily correlated ($r = 0.66$). The least correspondence was found for the social domain ($r = 0.14$). The two instruments cover different aspects of quality of life. The items of the EORTC-QLQC30 concentrate largely on the physical domain and its consequences. For example, its social functioning subscale addresses the social role implications of physical limitations whereas the FACT-G social and family subscale concentrates on social support and emotional attachments. The FACT-G consequently seems to have a broader coverage of the possible dimensions of quality of life that could be affected by a cancer diagnosis whilst the EORTC-QLQC30 may be more appealing to clinicians interested in physical impairment. For the purpose of my research, I am interested in the effects of a cancer diagnosis across a number of quality-of-life domains and the FACT-G is the most appropriate measure.

Benefit finding

Previous research has shown that individuals may feel both negative and positive emotions (Schroevers et al 2000, Watson & Clark 1997). Although cancer is likely to cause distress and disruption, there is also the possibility that aspects of the experience can be viewed as beneficial. For example, cancer patients have reported that their personal relationships have been strengthened by the experience, that they have made positive changes to future plans, activities or priorities, and that they have an enhanced sense of purpose (Cordova et al 2001, Curbow et al 1993, Gritz et al 1990). These positive changes in response to cancer have sometimes been labeled 'benefit finding' (Antoni et al 2001).

The relationship between benefit finding and distress is unclear. Sears, Stanton and Danoff-Burg (2003) report that there is no relationship between benefit finding and distress a year after diagnosis in a sample of 92 early-stage (Stages I and II) breast cancer patients. Tomich and Hegelson (2004) used a larger sample (N = 364) and included breast cancer patients with more advanced disease (Stages I, II and III). They found that initial benefit finding (assessed four months post-diagnosis) predicted increased distress nine months later. Carver and Antoni (2004) contradict this finding by showing that benefit finding related to decreased distress and depression four to seven years after surgery in a sample of 96 breast cancer patients (Stages I and II only).

These inconsistent findings could be due to differences in the characteristics of the samples. Particularly, stage of disease appears to interact with benefit finding. Lechner et al (2003) used a mixed-cancer sample (N = 83), representing all four disease stages, to explore the relationship between stage and benefit finding. They found a curvilinear relationship such that those with

Stage II had significantly higher benefit finding scores than either those with Stage I or Stage IV disease. They hypothesise that early stage disease may not be sufficiently stressful to provoke the type of life re-examination associated with benefit-finding, and that also very high levels of threat associated with very advanced disease would preclude benefit-finding. In the study by Tomich and Hegelson (2004) they also report that women with Stage II disease experience more benefits than those with Stage I. Stage III patients had a higher mean benefit finding than either Stage I or II patients, but this did not reach statistical significance. Importantly there was also an interaction between disease stage and benefit finding on negative affect. Patients with higher benefit finding and advanced disease stage at the initial assessment (four months post-surgery) had worse negative affect and mental functioning at subsequent assessments (3 months and 9 months after T1) compared to those with lower disease stage. These findings indicate that studies that exclude advanced disease stages (as in the studies by Sears et al and Carver and Antoni) will find different relationships between benefit-finding and distress than those studies that include these patients.

There is some emerging evidence regarding the relationship between SES and benefit-finding. Carver and Antoni (2004) report that lower education is associated with increased benefit-finding. The study by Tomich and Hegelson (2004) also reports an association between lower SES (education, occupation and income) and increased benefit finding. They argued that lower SES groups may typically experience more hardships in their lives and thus have more experience of trying to find something positive from a negative situation. Supporting evidence for this is that individuals who experience more traumatic life events often do report more benefits than those who experience

fewer traumas (Cordova et al 2001, McFarland & Alvaro 2000). Although more work is needed to replicate these results, if we consider benefit finding as a psychological outcome in its own right, regardless of its possible association with distress, then this could be one area in which lower SES groups have an advantage over high SES groups.

Cancer and Social Outcomes

Social difficulties

In addition to the impact of a cancer diagnosis on psychological outcomes, it can also lead to functional impairments that have a profound impact on social activities, from ability to work and participate in leisure and community activities, to carrying out basic domestic chores (Malone et al 1994). Cancer patients also report worrying about money and experience problems within the family (Macleod et al 2004). Some level of functional impairment can remain for a number of years after diagnosis and treatment. One study by Chirikos et al (2002) of the economic consequences of functional impairment in breast cancer survivors reports that survivors were more impaired than controls even five years after diagnosis. Breast cancer survivors were also more likely to work less and experienced reduced earning capacity. Another study has shown that the difference in employment status between cancer patients and age and gender-matched referents is small, but significant (50% employment amongst cancer patients compared to 55% in referents). The difference is largely due to many cancer patients opting to take early retirement (Taskila-Abrandt et al 2005).

Recent work in this area by Wright and colleagues (Wright et al 2001, Wright et al 2002, Wright et al 2005) has tried to systematically assess the

types of social difficulties encountered by cancer patients and led to the development of a questionnaire measure to assess these problems (Wright et al 2005). They initially carried out focus group discussions with 96 cancer patients. Eight areas of concern were identified by patients: i) difficulties managing in the home, ii) difficulties with health and welfare services, iii) financial problems, iv) employment issues, v) legal problems, vi) relationship difficulties, vii) sexuality and body image problems, and viii) difficulties participating in leisure activities. The most frequently endorsed problems were those to do with relationships and communication, but problems with finances, employment and domestic chores were also widely reported. Being female, younger and receiving palliative care was related to increased reporting of problems (Wright et al 2002). This demonstrates that a diagnosis of cancer can have far-reaching consequences for patients' financial situation, ability to maintain independence, and capacity for participation in the social world at a level prior to diagnosis.

Medical interactions

Quality of medical interactions is likely to affect patients' ability to maintain psychological health across the spectrum of cancer-related stressors from screening, through diagnosis, treatment and survival. Satisfaction with care in oncology is related to the communication and interpersonal skills of physicians, information provision, and organisation of services (Davidson & Mills 2005). The Calman-Hine report (Calman & Hine 1995) proposed that the best practice in oncology services would include a patient-centred approach with physicians providing clear information and assistance about treatment options and outcomes. This reflects a move throughout medical practice

towards a 'concordance' model of patient care (Ferner 2003). This replaces the authoritarian or compliance model where there is a passive patient receiving treatment from a paternalistic doctor. The concordance model proposes a partnership between health professionals and patients, allowing the patient to become more active in decisions relating to their care.

In studies of patient satisfaction with oncology staff, patients tend to express high levels of satisfaction with their interactions with medical staff (Shilling et al 2003) and with the information that they have received (Sapir et al 2000). Despite expressing these high levels of satisfaction and comprehension, many patients continue to have an inaccurate understanding of their disease status, the types of tests they have undergone and the treatment they have received (Gattellari et al 1999, Mackillop et al 1988, McGregor 2003, Sapir et al 2000). This discrepancy may arise because of the type of language used in consultations, particularly the use of ambiguous terms such as 'seedlings', 'spots' and 'growths' and medical jargon such as 'benign' 'metastasis' and 'tumour', which are not terms readily understood by the lay public (Chapman et al 2003, Sapir et al 2000). New patients may be unable to take in new information about the disease, selectively remember only optimistic information, or selectively fail to attend to the word 'cancer' when it is used because of the stressful nature or receiving a cancer diagnosis (Moore & Estey 1999, Purandare 1997). These sorts of comprehension problems are related to the use of 'denial' coping strategies where patients seek to minimize or ignore the impact of having the disease (Gattellari et al 1999). Their have been a number of studies that examine good practice in breaking 'bad news' to cancer patients (Fallowfield & Jenkins 2004, Shilling et al 2003). Patients want their doctors to

speak in simple terms using unambiguous language and to be honest, compassionate and supportive (Fallowfield & Jenkins 2004).

Patient assessments of clinician communication skills and their experience of receiving a cancer diagnosis are related to subsequent levels of anxiety and depression (Schofield et al 2003). In a survey of 60 women with early stage breast cancer, three aspects of care related to psychological adjustment: caring (interpersonal skills), competence (technical expertise) and understanding (communication skills) (Mager & Andrykowski 2002). Overall levels of satisfaction were unrelated to levels of distress or anxiety in this study, although other studies show that satisfaction scores relate to these aspects of care as well as to organisation of health services such as waiting times and provider-delay (Davidson & Mills 2005).

Oncologists recognise that their communication skills may be lacking due to inadequate training and that this contributes to their own experience of stress and satisfaction (Ramirez et al 1996). Fallowfield and colleagues have been testing and running communication skills training for clinicians over a number of years and have run a randomised control trial of the effectiveness of the training course. Their training programme improves the use of empathy, open rather than closed questioning, checking understanding, responding to patient cues, and encouraging fewer interruptions (Fallowfield et al 2002). This training is successfully integrated into oncologists' normal practice with improvements showing persistence when measured up to 15 months after the training course (Fallowfield et al 2003). These studies show that health care professionals are receptive to training and that significant improvements can be achieved. These improvements in communication skills have only a small, statistically non-significant, positive effect on levels of patient satisfaction showing that other

areas, such as service delivery (e.g. waiting times and administration) are as important for patient satisfaction as communication skills (Shilling et al 2003).

Patient satisfaction surveys are highly variable in terms of quality. Sitzia (Sitzia 1999) reviewed the reliability and validity of patient satisfaction data. He found that only 6% of the 181 studies reviewed reported either criterion or construct validity together with content validity and reliability. 80% of studies produced new satisfaction instruments with a further 10% modifying existing instruments. This is because most studies are context specific and consequently need a variety of different measures. This issue is being addressed in the area of cancer patient satisfaction. For example the EORTC-QLQ SAT32 is in the process of validation (Bredart et al 2004). This is a measure of patient satisfaction in oncology that is undergoing extensive testing. The areas measured include technical skill, information giving and interpersonal qualities for both doctors and nurses. There is also a section on organisation of care including waiting time, accessibility and comfort. This addresses the areas related to satisfaction identified in the literature and should prove a useful tool when it becomes available. An issue with patient satisfaction surveys is that high levels of satisfaction are often reported (Sitzia 1999) despite contradictory observations of unmet care needs (Sanson-Fisher et al 2000).

Sitzia (Sitzia 1999) comments that only a low proportion of studies use qualitative methods to observe patient satisfaction and that this could be valuable for descriptive use and theory development. Qualitative interviews may be more effective at revealing dissatisfaction than quantitative surveys as they allow patients to answer in an open-ended manner in their own terms. There are some recent qualitative papers that explore aspects of doctor-patient communication in cancer patients (e.g. (Freedman 2003, Leydon et al 2000,

Wright et al 2004)). Freedman (Freedman 2003) observed 25 breast cancer patients with 12 different physicians during their medical encounters and found that patients made decisions regarding their treatment depending on their personal and emotional reaction to the physician. This meant that they followed the advice of the physicians that they felt they 'got on with' best. Patients also place importance on creating a good friendship or positive social environment with their physicians. This was one way of establishing a form of control in that a trusting relationship would result in them receiving better treatment from their physician. A limitation of this study was that the majority of the participants had relatively high SES (completed high school with private medical insurance). Low SES patients may have different experiences and different methods for evaluating their care.

Wright et al (2004) also found that the social and interpersonal aspects of medical interactions were more important to breast cancer patients than the actual quality of the information that they received. They audiotaped consultations between patients and physicians and then interviewed both again 1-5 days later. Patients emphasised the importance of being seen as an individual rather than 'just another patient'. They felt that establishing a relationship by talking about issues unrelated to their disease would mean that their physician would remember them and attend to their needs better. This also highlighted the attachment needs patients had with their doctors during a time of threat. Patients made judgements about trust and level of expertise based on their physicians interpersonal skills, such as showing respect and care by talking at eye level, giving patients the option to choose treatments and taking the time to provide the patient with reassurance. Both of these qualitative papers highlight the importance of doctor's interpersonal skills as a

means of conveying trust and expertise rather than the content or type of information that they give to their patients. These papers were both observations of interactions with breast cancer patients. Male cancer patients or patients with a different cancer site may reveal different attitudes. Future research would benefit from using a mixed-gender sample and by targeting recruitment according to socio-economic group so that views from a wide range of social backgrounds can be observed.

A recent review of the literature by Willems et al (2005) found that lower SES patients received less positive emotional reassurance, a more directive consulting style and less diagnostic and treatment information from their physicians. Lower SES patients also experienced less control over their communication with their physicians. This review assessed papers from 1965 to 2002 and included 12 papers in the review. The majority of the papers in this area were published some time ago with only 2 papers dating from 2000 and none more recently than that. Research in the area is still sparse and more up-to-date data is required. Two more recent papers (Macleod et al 2004, van Ryn & Fu 2003) show that socio-economically deprived breast cancer patients receive less information from hospital specialists than more affluent women (Macleod et al 2004) and that doctors communicate better with people they perceive to be of the same social class as themselves (van Ryn & Fu 2003). Qualitative interviews to explore this issue will also help to provide a stronger basis on which to form recommendations for changes in medical practice.

Conclusions

In Chapter 1 I explored the relationship of SES to psychosocial responses to stressors. I concluded that there was still a scarcity of research that examined differential vulnerability of SES groups in response to real-life stressors. In this chapter I have demonstrated that there are a number of cancer-related stressors from screening through diagnosis, treatment and survival that have the potential to impact on psychosocial wellbeing and reason to believe that SES may be an important moderating variable. The research studies in this thesis will use the framework of cancer-related stressors to examine the relationships between SES and psychosocial outcomes in response to stress.

CHAPTER 3

Measurement of socio-economic status

The term, 'socio-economic status', refers to people's positions within the social and economic structure of society. It encompasses ideas of social class, social status or prestige, and material living conditions (Bartley 2004). Hierarchies are an integral part of society. One aspect of this stratification arises from ownership, production and exchange of economic resources. Material living standards can be reflected in measures of income, or wealth, including various assets, that affect the individual's purchasing power and ability to access resources. Social class has largely been defined in terms of people's occupation. Occupation can be used as an indicator of social relations in the settings of employer-employee relationships, ownership of property, types of labour contract and cultural norms within different occupational sectors (Rose & O'Reilly 1998). Occupation is clearly linked with ideas of status, prestige or community ranking. Status within society is not necessarily linked to material assets. Occupation determines income, but status can be obtained independently of material advantages. There are high prestige occupations that are relatively poorly paid and lower status occupations that are highly paid (e.g. research scientist vs advertising executive). Another important indicator of social and economic position is level of education. Educational achievements can reflect both class and material conditions because wealth is required to secure a high level of education and a high level of education is also required to secure higher status occupations.

Measures of Social Position

Occupation

In the UK, social position has most often been measured using occupational class systems. The Registrar General's classification system (RGSC) of occupational status was developed for the 1921 census data (Stevenson 1928) and was widely used. It classified people into 6 categories (3 manual and 3 non-manual) according to skills and community status. The RGSC is criticised for lacking theoretical content and explanatory power and for not being applicable to people out of work, young people, retired people, or to women (Chandola 1998, Rose & O'Reilly 1998, Szreter 1984). This system classifies housewives as 'unoccupied' and it is difficult to assign them a class, although there is better success when classifying women according to a husband's occupation.

The Registrar General's classification system, and its various updated versions, have been replaced by the UK National Statistics Socio-Economic Classification (NS-SEC) (Rose & O'Reilly 1998) as the official UK government measure of social class. The NS-SEC is explicit about its theoretical basis. It measures social class based on the differences between employment relations and conditions. The focus is on occupational relationships and it divides people into: those that are employers and buy labour and have some degree of control and authority over it, employees who sell labour and are under control of employers, and the self-employed who do neither. These categories are then further subdivided depending on 'service relationship' which takes into account degree of autonomy, authority, salary increments, benefits and opportunities.

One of the problems with occupational measures of social class has been that they cannot accurately classify those outside the workforce. People

outside of work include not only the unemployed, but also students, home-makers and retired populations. It may not always be appropriate to classify people based on their past employment. Women may work intermittently between periods of increased domestic responsibility and their jobs may not reflect their household circumstances. Classifying women on the basis of their partner's occupation is also problematic and not always appropriate or possible. Similarly, retired people's current material circumstances may be greatly reduced compared to what it was during periods of paid employment. These problems have not been successfully addressed under the new NS-SEC classification system. Drever et al (2004) classified adults aged 25-64 into socio-economic groups as defined by the NS-SEC using data from the 2001 census. They report that twice the proportion of women aged 25-64 were unclassified compared with men of the same age (13.7% and 6.3% respectively). This disparity was apparent across all age groups. Drever et al's analysis was restricted to those under the age of 65 and over the age of 25 because the retired and student populations could not be usefully classified. Among women aged 60 to 65 years nearly 40% of women were unclassifiable. The NS-SEC may not be appropriate to use in research studies which focus on these populations.

Education

Years of education has the advantage of being a continuous measure, with meaningful cut points (e.g. in the UK, completion of GCSE's, A-levels, University) that is applicable to the whole population, including women and minority groups (Berkman & Macintyre 1997). Education is also linked to access to more prestigious occupations and the better material benefits they

entail. If psychosocial resources are important links for explaining the relationship between SES and health, then measuring education may be more important because of its links to cognitive development and behaviours. However, because educational achievement is generally stable over the course of a lifetime it cannot reflect fluctuations in social and economic circumstances. Additionally, access to education has changed dramatically over the past couple of generations making comparisons between older and younger populations difficult.

Measures of Material Living Standards

Income

Income provides information about an individual's purchasing power and potential access to resources. Measuring income has appeal because it can be used as a continuous measure with a broad range. However, it cannot fully reflect a person's economic status as it fails to take into account, for example, inherited wealth, material assets and savings (Berkman & Macintyre 1997). Additionally, any measure of income needs to be supplemented by information concerning the number of people that the income is used to support. Finally, income is often poorly reported in surveys because people consider it to be sensitive information that they would rather not divulge (Berkman & Macintyre 1997).

Assets

A relatively novel way of measuring SES has been to assess various material assets of the individual. In particular housing tenure and car ownership have independent power to predict mortality as well as adding power when

used in conjunction with other measures such as occupation (Filakti & Fox 1995, Wannamethee & Shaper 1997). These measures are also equally applicable to men and women, to those beyond working age (Filakti & Fox 1995) and to the younger population such as adolescents (Wardle et al 2002).

Resources are not simply markers for income and wealth, although both car and home ownership are highly correlated with income and occupation (Rickards et al 2004). Home ownership may reflect higher standards of living in terms of the fabric of the dwelling including protection from noise, damp and cold as well as quality of the area, such as vandalism and access to local amenities when compared to homes that are rented from local authorities or private landlords (Ellaway & Macintyre 1998). Car ownership may improve access to employment and local facilities such as health services and open spaces.

Both car and home ownership have increased in the UK over recent years. In 1971, 49% of households were owner-occupied, this had increased to 69% by 2002 (Rickards et al 2004), possibly reflecting such policies as the 'right-to-buy' that was introduced in the 1980s. 73% of households had access to a car in 2002 compared with 52% in 1972 (Rickards et al 2004). This breaks down into 44% of households with one car and 29% of households with two cars or more (Summerfield & Babb 2004). The high levels of car and home ownership imply that those without these items are amongst the most deprived in the UK. However, these figures vary widely between urban (low ownership) and rural (high ownership) locations with nine London boroughs and Glasgow city reporting levels of car ownership below 50% (Summerfield & Babb 2004).

Asset-based indicators of SES are useful because respondents are much more likely to complete items about car and home ownership compared

to questions about levels of income. For example, Macintyre et al (1998) report that in their sample of 1710 individuals involved in the West of Scotland Twenty-07 Study, 148 (8.7%) respondents failed to answer questions about income compared to only 2 (0.1%) people with missing data on car ownership and another 2 missing for home ownership. Measuring car and home ownership consequently have a number of benefits in terms of accurately assessing SES.

Area-level Markers of SES

There are also measures which catalogue SES at an area level. This involves linking individual postcode data to an area-level, composite score based on census information. This type of measure can be useful because postcode data maybe more readily available or easier to collect than other more intrusive questions about a person's socio-economic background. Individual-level data may be more likely to be either missing or unreliable in some way.

On theoretical grounds the relationship between SES and health may be in part due to the material environment of the area that the individual lives in (Yen & Syme 1999). Some studies suggest that area-level measures make an independent contribution to the link between SES and health over and above individual factors (Robert et al 2004, Shohaimi et al 2003). Other studies suggest that appropriate adjustment for individual level markers of SES reduces the magnitude of the associations between neighbourhood SES and health (Reijneveld & Schene 1998). A review by Pickett and Pearl (2001) found that 23 out of 25 studies reported statistically significant area-level effects on health outcomes after controlling for individual-level SES. However, they noted that studies which included multiple individual-level markers reported weaker area-level effects than studies which used only a single individual-level item. This

implies that area-level effects could be proxies for unmeasured individual-level effects.

Studies that compare the relationship between area-level and individual-level markers of SES sometimes find poor agreement. For example, Demissie et al (2000) report that in their study of 943 children within 155 small enumeration areas in Quebec, individual and area level markers of SES corresponded exactly only 28.7%. Similarly Wardle et al (2002) report a correlation of 0.42 between individual and area level markers that, although a relatively high and significant correlation, still indicates a large proportion of misclassification. This lack of correspondence could suggest that individual and area level markers capture markedly different aspects of SES or alternatively that one or the other measure is inaccurate. It remains unclear whether area-level effects of SES on health reflect access to health-promoting local resources or are surrogates for unmeasured aspects of individual SES.

Regardless of this issue, another problem with area-level markers relates to the choice of the size of area that is measured. In England and Wales, the most well known area-level score is the Townsend Index (Townsend et al 1988). This is a measure of deprivation based on access to cars, percentage unemployed, percentage owner occupiers and degree of overcrowding. In the 1991 census, a score was produced for each enumeration district in England and Wales. There were approximately 130,000 enumeration districts with roughly 200 households per district. Individual's postcode information can be linked to their enumeration district and consequently every individual can be assigned a Townsend score. Measuring SES at a neighbourhood or area level implies that the population within that area is relatively homogenous and, at the small-area level of enumeration district, the likelihood of this being true is

increased. However, efforts to protect confidentiality have meant that the 2001 census no longer produces information at this small-area level. The 2001 census data does hold information at 'output area' level (approximately 125 households) rather than enumeration districts, but detailed information at this level is withheld. The Townsend Index is still calculated at ward level, of which there are only 8850 (with approximately 5000 residents in each) within England and Wales. This increases the likelihood of socio-economic heterogeneity, thus reducing the accuracy and relevance of the measure. Other studies and reviews also support the use of area-level measures that are based on the smallest and most homogeneous census-defined region that is feasible (Hyndman et al 1995, Krieger et al 1997) in order to improve validity. As a result, the Townsend Index using the 1991 census data may be more effective than the information produced using the 2001 data. Data collected prior to 2001 can confidently employ the Townsend Index using the 1991 census data. As the time lag between the 1991 census data collection and the data collection period of new research studies' increases, the Townsend score based on the 1991 data becomes more unreliable. Studies with data collection since 2001 should cease to employ the 1991 data as a source for calculating Townsend scores. The dilemma is that the new scores from the 2001 data will also be less accurate because they are based on larger areas. This cautionary note will also apply to other area-level measures such as the more modern Index of Multiple Deprivation (Department of the Environment 2000).

Subjective SES

An alternative approach to measuring SES using the objective markers discussed so far is to assess individual's perceptions of their own socio-

economic position. Wilkinson (1999) has argued that the social comparisons that people make in relation to their own position within society's hierarchies compared to others could be more important for determining health rather than absolute level of SES. It may be that subjective SES is more accurate than objective SES as it allows the individual to take into account the special circumstances of their own lives that the broader categories of the objective measures cannot include.

A one-item measure that assesses subjective SES has been developed recently by Adler et al (2000). It takes the form of a drawing of a ladder on which individuals place themselves. The ladder has ten rungs with those who are the best off in terms of income, education, and occupation at the top and those who are worst off at the bottom. Adler et al (2000) tested this measure in a sample of 157 women. Subjective SES was more strongly and consistently related to psychological and physical health outcomes than objective SES markers. The associations between subjective SES and health remained after controlling for objective SES and negative affect.

A potential problem with this type of marker is that there may be overlap with psychological functioning. People who have depression or low self-esteem could be inclined to assess their social position as somewhat lower than is actually the case. Singh-Manoux et al (2003) explored how people made decisions about their subjective SES using regression models with participants from the Whitehall II study. They found that the most important predictors of subjective SES were employment grade, household income, education, satisfaction with standard of living and feeling of financial security. Psychological functioning (hopelessness, control, mental health, vigilance, hostility, and optimism) although correlated with subjective SES were not

independent predictors of subjective SES. This suggests that the subjective SES measure is a measure of SES and not a proxy for psychological functioning. However, this one study cannot be taken as conclusive because other unmeasured aspects of psychological functioning, particularly self-esteem, may have an impact on subjective assessments of SES. Nevertheless, one of the potential benefits of using this kind of measure is that it should be equally applicable to all sections of the population – young and old, male and female. It therefore overcomes some of the problems associated with objective markers that are based on either occupation or income.

Conclusions

The view of SES implicit in these measures is that its relationship to health is based around social position as well as material well-being. SES represents access to resources in terms of money, knowledge and people. The indicators described here are used either individually or in a combined format to access the various different aspects of SES. Each of the methods has merits and difficulties. The large-scale epidemiological studies which first bought to light the relationship between SES and health did not have a sound a priori theory regarding how this link is established. This makes it hard to choose an appropriate measure.

Additionally, there are clearly problems with accurately assessing SES amongst older age and retired populations, (the majority of cancer patients) that are studied in this thesis. One study that examined the use of seven different socio-economic indicators (occupation, education, income, housing tenure, household resources, Townsend indicators, and car affordability) in a sample of 3543 older adults (age 55-75 years) reported that all indicators were associated

with differences in self-reported health, but that combination measures, rather than single indicators, were more effective. They concluded that best measurement approach is to use a combined score based around either occupation or education paired with household resources (Grundy & Holt 2001).

I have decided that the best strategy may be to take multiple measurements, using separate markers (including income, Townsend Index and subjective SES) and also by forming a composite score. The composite score is based on car and home ownership as well as level of educational achievement. This measure has a number of advantages. Level of education, as discussed, is a relatively stable trait that applies to people who are not currently employed (retired, homemakers and unemployed) thus by-passing many of the difficulties encountered using occupational measures. Educational achievement is sensitive to age and birth cohort, but the studies included in this thesis concentrate on populations with relatively narrow age ranges. Education is also clearly linked to social prestige or status, as discussed. Car and home ownership measure aspects of material deprivation, rather than social deprivation. Both of these items should be more sensitive to changes in circumstances and are more acceptable measures of material assets than questions directed about income, which are often poorly completed. Combining these items produces a measure of socio-economic status based on actual resources and status or prestige. This measure has successfully been used in other research studies (Wardle et al 1999, Wardle et al 2004). All of the SES markers used in this thesis are based around the proposal that there will be an incremental gradient in wellbeing from lower to higher SES rather than categorical differences between 'classes' or between extremes of 'rich' and 'poor' (Marmot 2004).

CHAPTER 4

Outline of Research Studies

From the literature review, it is apparent that it would be valuable to understand more about how SES moderates reactions to real-life stressors. This is both because it will make a contribution to understanding the SES-health relationship, and because it will be useful for understanding the needs of lower and higher SES people when faced with particular stressors. I am using cancer-related stressors as a framework for examining this issue because cancer is a major stressor that can strike people from any SES group, and cancer clinicians could find it useful to know more about how SES influences responses to the disease. The research studies in this thesis will specifically investigate the following topics:

Study 1: Examines SES differences in psychological reactions to colorectal cancer screening in a population-based survey of older adults. I propose that cancer screening represents only a moderately stressful situation, but that different screening outcomes will be more or less stressful depending on their prognostic significance. The study examines SES differences in reactions to different screening outcomes and investigates whether SES affects psychological adjustment over time. The results will demonstrate whether or not this moderate type of stressor exacerbates SES differences in psychological wellbeing and can be compared to the results for the effect of more severe stressors that are examined in the subsequent studies.

Study 2: Examines SES differences in psychological reactions to receiving different disease stage diagnoses in a sample of colorectal cancer patients. Receiving a diagnosis of cancer represents a more severe stressor than undergoing cancer screening, explored in the previous study. This may be a situation more likely to exacerbate any SES differences in psychological adjustment. Again, differences in disease stage at diagnosis have prognostic significance (as in the case of different screening outcomes in the previous study) and could be experienced as more or less stressful. SES may interact with characteristics of stressful situations (here represented by disease stage) to differentially affect psychosocial outcomes.

Study 3: Uses a qualitative methodology to investigate the relationships between patients and medical staff and explore whether experiences of medical care differ according to patients' SES. The literature review indicated that interactions with medical staff were important for psychological adjustment and that experiences may differ by SES, but this has remained an under-researched topic. Medical interactions are studied quantitatively in Studies 2, 4 and 6, but the qualitative analysis used in this study complements the quantitative approach by providing a richer and fuller account of patients' experiences.

Study 4: Examines SES differences in psychosocial outcomes according to different disease stage diagnoses and different treatment regimens in a mixed-cancer patient sample (breast, prostate, and colorectal). This study aims to replicate and confirm any results seen in Study 2 using a larger,

mixed-cancer patient sample and additionally explore any SES interactions with different treatment regimens, and the presence of co-morbid illnesses on psychosocial outcomes. Undergoing certain treatments changes the amount of stress experienced by cancer patients e.g. patients who receive surgery will be more physically debilitated than those that do not. Similarly the presence of a co-morbid illness in addition to cancer would be expected to more stressful. This widens the assessment of SES interactions with different cancer-related stressors on psychosocial outcomes.

Study 5: Examines the association between SES and psychosocial resources in a mixed-cancer patient sample and the relationship between psychosocial resources and psychosocial wellbeing. The literature review suggested that psychosocial resources, such as optimism, control, and social support could be related to SES and psychosocial wellbeing. This study uses the same dataset as Study 4 to explore these relationships.

Study 6: Examines the relationships between SES and psychosocial adjustment to a cancer diagnosis over time. It may be that different SES groups are able to psychological adapt to a cancer diagnosis more efficiently. Cancer patients are followed up at 1-3 months post-diagnosis and 9-12 months post-diagnosis to examine this topic. The same sample as that used in Studies 4 and 6 are used in these analyses.

The studies cover a wide-range of cancer-related stressors from less to more severe and explore the effect of SES on psychosocial adjustment in

these different situations. The analytic strategy involves i) comparing SES groups cross-sectionally ii) an examination of interactions between SES and the characteristics of the cancer-related stressor (e.g. disease stage or treatment type) and iii) SES differences in psychological health over time. More than one level of cancer stress is explored in the studies, such as different disease stages, different screening outcomes or adjustment over time so that reactions to the situation are examined in relation to SES rather than population level differences in wellbeing by SES. This will improve the understanding of individual differences in reactions to cancer-related stressors which can serve to inform supportive care strategies. This will also further the knowledge of how SES can affect reactions to stress leading to better awareness of the ways in which inequalities in psychological health arise.

CHAPTER 5.

Study 1: Socioeconomic status differences in adjustment to bowel screening[2]

Introduction

The present study tests the idea that lower SES groups will have a more emotionally charged response than higher SES groups to a moderately stressful medical encounter. The study uses emotional reactions to a cancer screening examination to test this hypothesis.

The stressor investigated in this study is a screening examination for early detection of colorectal cancer. Colorectal screening is not currently included in the national screening programme in the UK, but a randomized controlled trial of the efficacy of flexible sigmoidoscopy (FS) is in progress (UK Flexible Sigmoidoscopy Screening Trial Investigators 2002). This study uses data from this trial. FS screening involves endoscopic examination of the distal colon to identify precancerous changes (polyps) and early, asymptomatic lesions. FS is followed up with colonoscopy if there are indications of disease in the proximal colon. The bowel preparation for the FS examination (a self-administered enema) is a novel procedure for most adults and the endoscopy itself can be embarrassing and uncomfortable. In this study, people who were found to have polyps waited another two weeks before being given the 'all-clear', whilst those needing colonoscopy waited an average of six weeks for the appointment, then endured another more invasive and uncomfortable procedure. The worry associated with the possible detection of cancer also added to the potential stress.

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[2] A version of this chapter was published in *Psychosomatic Medicine* (2005) and a copy is included in Appendix III.

Previous research into the psychological impact of cancer screening suggests there is increased distress both in anticipation of attending screening, and while waiting for follow-up tests (Steggles et al 1998, Wardle & Pope 1992). Longer-term adverse consequences have been identified among women who are recalled for further investigations after mammography screening (Brett et al 1998, Olsson et al 1999). I judged that the FS screening procedure would be mildly stressful and that the experience of people recalled for colonoscopy would be moderately stressful, thus providing an appropriate setting to look for SES differences.

The data available from the trial included measures of anxiety and cancer worry before and after the screening examination(s) in a subset of trial participants (the longitudinal sample). This meant that it was possible to compare changes in emotional wellbeing over time between SES groups. I expected that the lower SES groups would be more anxious beforehand and would find the examination procedure more threatening, resulting in more adverse emotional outcomes in these groups. The longitudinal data also included both an area-level (Townsend Index) and an individual level (based on level of education, car and home ownership) index of SES. This allowed comparison of the results using two different socio-economic markers.

Data on psychological well-being 3 months after screening were available for the whole screening group (the post-FS sample). This permitted an examination of SES (Townsend index only available for this sample) differences in well-being in people who received negative (clear) results compared with those who had polyps detected and removed during FS and those who were referred for colonoscopy. I hypothesized that the screening

experience would be most stressful for those who were referred for colonoscopy, and predicted that there would be an interaction between SES and screening outcome in post-screening well-being.

Hypotheses

1. There will be SES differences in psychological adjustment to flexible sigmoidoscopy screening such that lower SES groups will be more adversely affected.
2. There will be SES differences in psychological adjustment to different screening outcomes, such that lower SES groups will experience greater distress than higher SES groups when being referred for colonoscopy.

Method

Participants

Data for these analyses come from the UK Flexible Sigmoidoscopy Trial; a randomized controlled trial of the efficacy of a single FS examination in older adults (Atkin et al 2001, UK Flexible Sigmoidoscopy Screening Trial Investigators 2002). Fourteen geographical centres throughout the UK were included in the trial. There was at least one centre in each Regional Health Authority in England, two in Wales and one in Scotland. The trial involved a general population sample of 354,262 men and women age 55-64 years old, identified from 505 General Practices. Exclusion criteria included: inability to provide informed consent, history of colorectal cancer, adenomas or inflammatory bowel disease, severe or terminal disease, life expectancy of

less than five years, and having received a colonoscopy or sigmoidoscopy in the previous three years. Those who were considered eligible for the trial by their GP were mailed information about FS screening. People who responded to the information letter and expressed an interest in attending (194,726) were randomized either to screening or usual care (no screening) in a ratio of 1:2. In total 57,254 respondents were randomized to screening, of whom 40,674 (71%) attended. Local research ethics approval was given for each of the participating centres.

Design and procedure

Background questionnaires had been sent to a randomly selected sub-set of participants (N = 5,942/57,254, approximately 10% of the randomized sample) around 5-6 months before they came for the screening examination in three centres: Portsmouth, Oxford, and Swansea. The questionnaire was seven pages long and consisted of items regarding demographics, health behaviours, attitudes to cancer and cancer screening, psychological well-being bowel symptoms and family history of bowel cancer (Appendix IV). This group comprised the smaller sample used to examine changes in emotional well-being from before to after the examination (the longitudinal sample). Follow-up questionnaires were sent to all screening participants, except those diagnosed with cancer (N = 140), 3 months after the first examination (N = 40,534, the post-FS sample). This questionnaire was also seven pages long (Appendix V) and measured satisfaction with the screening experience, psychological well-being, bowel symptoms and health behaviours.

The screening examination

The examination was carried out in a dedicated unit in the local hospital by a medical endoscopist. The procedure took around 5 minutes and the participants could watch the progress of the scope and any polyp removal on a screen. The design of the study is shown in Figure 1. 72% (N = 29,406) had no polyps detected and were given a letter confirming the negative result at the end of the examination. 9,607 (23.6%) had small polyps detected and removed at FS. 2,131 (5.3%) were referred for colonoscopy either at the time of the FS screen or because the polyps that were removed at FS showed high-risk pathology. The average time from FS to completion of colonoscopy was 6 weeks. All screened participants, except those diagnosed with cancer, were mailed a follow-up questionnaire 3 months after the FS exam to assess the psychological impact.

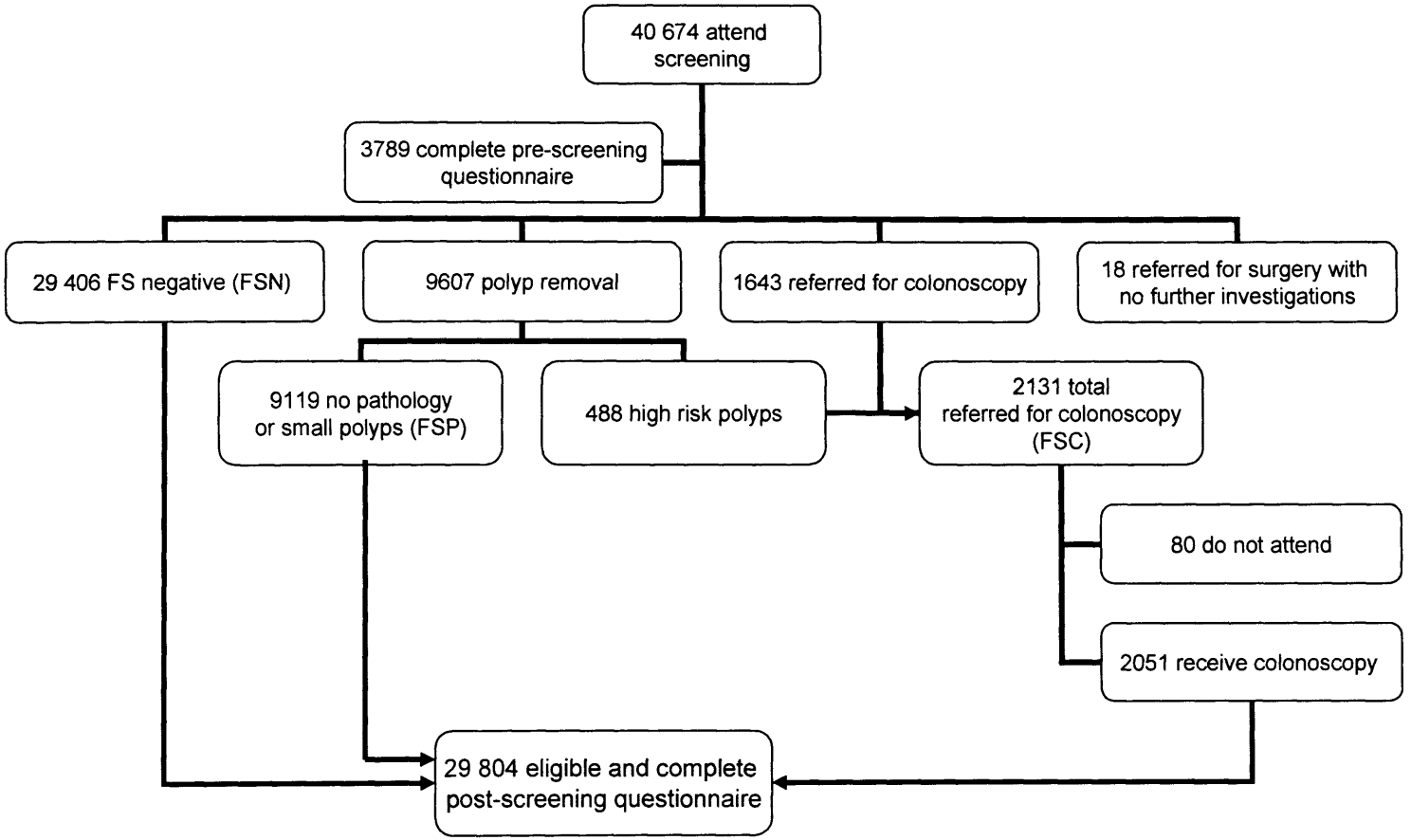
Measures

Socioeconomic status

Area-level indicator

SES was indexed using an area-level measure of socioeconomic deprivation that could be derived from postcode information within England and Wales. The Townsend Index (Townsend et al 1988) is based on levels of car ownership, housing tenure, unemployment, and overcrowded living conditions as recorded in the census across enumeration districts (on

Figure 1 Study design



average about 200 households). Each enumeration district receives a score based on its relative levels of deprivation. A score of zero represents the national average with negative values representing less deprivation (higher SES) and positive values representing more deprivation. Postcode information was collected for each individual and linked to enumeration districts; the Townsend score for the district was assigned to the individual. For the purposes of analyses, the scores were grouped into quintiles to form five categories with '1' indicating lower socioeconomic deprivation and '5' signifying higher deprivation. This classification results in five roughly, equal groups and consequently provides information about the relative deprivation of participants within the sample. This measure of deprivation was available for both the longitudinal and the post-FS sample. The data collection period for this study was between 1994 and 1999 and the Townsend index score was based on the data from the 1991 census.

Individual-level indicator

The longitudinal sample also recorded self-report indicators of SES. An individual-level indicator of socio-economic deprivation was measured using a score composed of three items: car ownership (yes/no), home ownership (yes/no), higher educational qualifications (some/none). Car and home ownership were selected because they are frequently used markers of deprivation and also correspond to items on the Townsend Index. Education is another widely used measure of SES and has the advantages of remaining stable over time and being applicable to members of society outside of the work force. A composite score was created with a range from 0-3. A score of '0' represents the most affluent (car owner, home owner and educational

qualifications) while a score of '3' represents the most deprived (no car, not home owners and no qualifications). This marker provides information about each individual's circumstances and is consequently a measure of that individual's actual or absolute level of deprivation. This individual data was not available for the post-FS sample.

Screening outcome

The three possible screening outcomes were: i) flexible sigmoidoscopy with a negative (clear) result (FSN), ii) flexible sigmoidoscopy in which small polyps were found and removed (FSP), and iii) flexible sigmoidoscopy followed by colonoscopy to examine the proximal bowel and remove large and numerous polyps (FSC). The small number of participants (0.34%, $N = 140$) who received a cancer diagnosis were not included in these analyses.

Bowel cancer worry

Worry about bowel cancer was assessed with the single item: "How worried are you about getting bowel cancer?" (Sutton et al 1994). Response options were: 'not at all worried', 'a bit worried', 'quite worried' and 'very worried'.

Psychological Well-being

The shortened (6 item) state version (Marteau & Bekker 1992) of the State-Trait Anxiety Inventory (STAI; (Spielberger et al 1983)) was included in both the pre-screening and post-screening questionnaire. The short form has good concurrent validity compared with the full form and good internal reliability ($\alpha = 0.82$) (Marteau & Bekker 1992). Item scores were summed to produce a scale from 6 to 24 with higher scores indicating greater anxiety.

At follow-up, participants were additionally sent the 12-item General Health Questionnaire (GHQ-12; (Goldberg et al 1997)). The GHQ is designed as a self-administered test to assess psychological distress in primary care patients (Goldberg 1978). It assesses present state in relation to usual state e.g. "in the last three months have you been able to face up to your problems?". The items have 4 response options: 'Better/more than usual', 'same as usual', 'less than usual', and 'worse/much less than usual'. The GHQ-12, which has good reliability and validity (Goldberg et al 1997), producing scores from 0 to 24 with higher scores indicating greater distress.

Positive consequences of screening were also measured at follow-up using six items from the Psychological Consequences of screening Questionnaire (PCQ; (Cockburn et al 1992)). All items started with the stem: "do you think that your experience of having the Flexi-Scope test has...?" followed by: "given you a sense of reassurance that you do not have bowel cancer", "made you feel more able to do the things that you normally do", "made you feel more hopeful about the future", "made you feel less anxious about bowel cancer", "made you get on better with those around you", "given you a greater sense of well-being". Response options were: 'not at all', 'a little bit', 'quite a bit', 'a great deal'. Items were scored 1-4 and scores were summed to produce a scale from 4-30 with higher scores indicating more positive consequences. The scale had good internal reliability (Cronbach's $\alpha = 0.86$) in this sample.

Analyses

In the longitudinal sample, repeated measures analysis of variance with deprivation quintiles as the between-subjects factor, time (pre to post screening) as the within-subjects variable, and screening outcome included as a control variable, was used to test for the hypothesized SES by time interactions for state anxiety and bowel cancer worry. For the analyses of SES differences in response to the different screening outcomes, we used the larger post-FS sample. Results were analyzed using analysis of variance with SES and screening outcome as the independent variables and age and gender included as control variables. Family history was not used in the analyses as a control variable because it was unrelated to SES and did not alter the results when included in the analyses. If, as we hypothesized, a positive FS test followed by colonoscopy is experienced as more stressful for lower SES participants, then we would expect to find an outcome by SES interaction for anxiety (STAI), psychological distress (GHQ) and positive consequences (PCQ).

Results

Longitudinal sample

3789/5,942 (64%) both attended screening and returned the pre-screening questionnaire. 3,535/3,789 (93.3%) also returned the post-screening questionnaire and therefore contributed data for the longitudinal analyses. The participants were 50.6% male (*N* = 1789) and 49.4% female (*N* = 1746). 97.5% were white (see Table 1). Their mean age was 60.74 (SD = 2.91) years. The mean Townsend score was -1.47 (SD = 2.66) (i.e. more

Table 1 Demographic characteristics – Longitudinal sample

		N (N = 3,535)	%
Gender	Male	1789	50.6
	Female	1746	49.4
Ethnicity	White British	3447	97.5
	Black	6	0.2
	Asian	17	0.5
	Other	10	0.3
	Do not wish to answer	22	0.6
	Missing	33	0.9
Education	No formal qualifications	1550	43.8
	Some formal qualifications	1806	51.1
	Missing	179	5.1
Car owner	None	327	9.3
	One	1948	55.1
	More than one	1214	34.3
	Missing	46	1.3
Home owner	Own	3146	89.0
	Rent	284	8.0
	Other	54	1.5
	Missing	51	1.4

affluent than the national average) with a range from -6.03 to 8.11. Area-level deprivation did not relate to age (F [4, 3460] = 2.09, NS) or gender (χ^2 = 0.42, df = 1, NS). The individual-level index of SES was related to age (F [3,3331] = 4.27, p<0.01) such that older age was associated with increased deprivation. Gender was also associated with individual-level SES (χ^2 (1) = 28.4, p<0.001) with more women represented in the most deprived category. The area-level and individual-level measures both included indicators of car and home ownership and were consequently highly correlated (spearman's rho = 0.32, p<0.01). However, this is lower than might be expected and suggests that there were a number of people who were designated affluent using the Townsend index but were deprived using the individual-level measure, and vice versa.

The overall mean level of anxiety at baseline was 9.83 (SD = 3.49). Univariate ANOVAs, controlling for age, gender and screening outcome, showed that there were significant differences in levels of anxiety and bowel cancer worry depending on area-level SES, both before (anxiety: F [3,3432] = 10.15, p<0.001, partial eta squared = 0.012, worry: F [3,3434] = 8.35, p<0.001, partial eta squared = 0.010) and after (anxiety: F [3,3420] = 12.00, p<0.001, partial eta squared = 0.014, worry: F [3,3414] = 7.49, p<0.001, partial eta squared = 0.009) screening. More deprived groups were more anxious and more worried about developing bowel cancer both before and after screening (see Figures 2 and 3). The partial eta squared indicated small effect sizes. Anxiety was reduced (F (1,3389) = 27.85, p<0.001, partial eta squared = 0.001) from before (STAI mean = 9.83; SE, 0.06) to after screening (STAI mean = 9.49; SE, 0.06), but there was no evidence for a differential

Figure 2 – Change in anxiety from before to after screening by quintile of socioeconomic deprivation (Area-level).

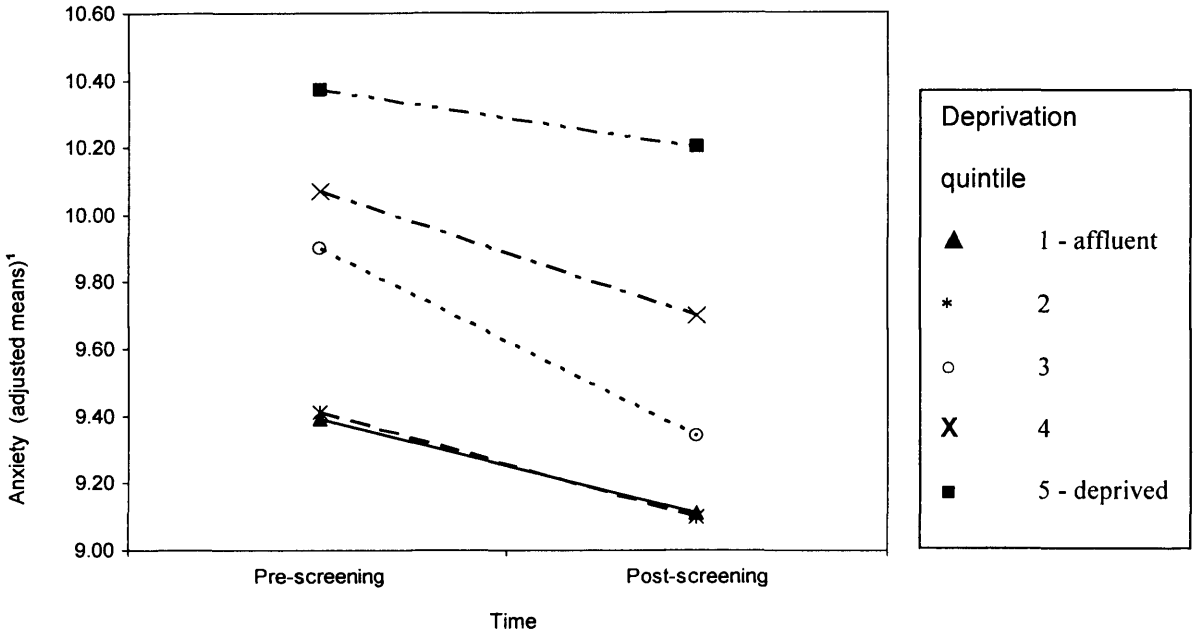
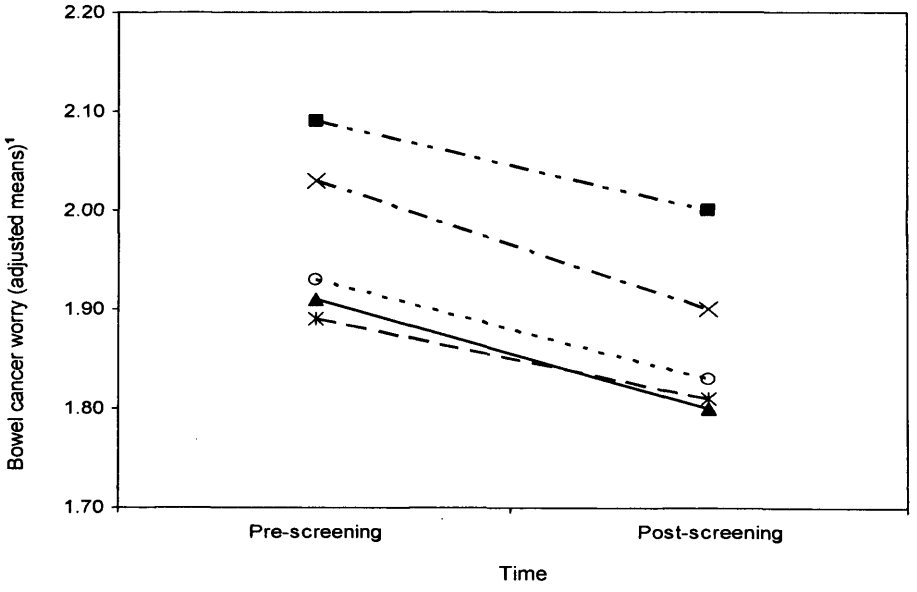


Figure 3 – Change in bowel cancer worry from before to after screening by quintile of socioeconomic deprivation (Area-level).



[1] Adjusted for screening outcome

Table 2 Area-level deprivation: Change in anxiety and worry about bowel cancer from before to after screening, controlling for screening outcome.

	Anxiety		Bowel cancer worry	
Area-level deprivation (Townsend)	Mean change	95% CI	Mean change	95% CI
Affluent 1	-0.29	-0.57 to -0.00	-0.11	-0.16 to -0.05
2	-0.32	-0.60 to -0.02	-0.08	-0.14 to -0.02
3	-0.58	-0.86 to -0.29	-0.10	-0.16 to -0.04
4	-0.37	-0.66 to -0.09	-0.13	-0.19 to -0.07
Deprived 5	-0.16	-0.45 to -0.13	-0.10	-0.15 to -0.04

effect across levels of SES. Bowel cancer worry also decreased significantly over the period of screening (F [1, 3383] = 55.96 p<0.001, partial eta squared = 0.001) (pre-screening worry mean = 1.97; SE, 0.01, post-screening worry mean = 1.87; SE, 0.01) but again the interaction with deprivation was not significant. Table 2 displays the mean change across each level of deprivation, showing that the reductions in both anxiety and bowel cancer worry were small.

The individual-level marker of deprivation revealed more about the socio-economic distribution of the sample. Table 1 gives details of the demographic characteristics of the sample. As can be seen, although there is a roughly equal distribution of those with (51.1%) and without (43.8) educational qualifications, very few people did not own a car (9.3%) or their

own home (9.5%). This indicated that the sample had relatively low levels of deprivation. Consequently the individual-level deprivation index had very few participants (N = 86, 2.4%) in the highest deprivation category and a disproportionate number in the most affluent category (*N* = 1653, 49.6%).

Similar results were obtained using the individual-level marker of SES as to those found using the area-level indicator. There was a significant effect for anxiety and bowel cancer worry, with more deprived groups reporting more anxiety worry before (anxiety: F [3, 3324] = 20.16, $p<0.001$, partial eta squared = 0.018; worry: F [3, 3308] = 29.85, $p<0.001$, partial eta squared = 0.026) and after screening (anxiety: F [3,3292] = 18.36, $p<0.001$, partial eta squared = 0.016, worry: F [3,3289 = 15.85, $p<0.001$, partial eta squared = 0.014) (see Figures 4 and 5). Anxiety (F (1,3276) = 10.04, $p<0.01$, partial eta squared = 0.002) and worry (F [1, 3255] = 17.70 $p<0.001$, partial eta squared = 0.001) reduced from before (STAI mean = 10.33; SE, 0.16; worry mean = 2.08; SE, 0.04) to after screening (STAI mean = 9.78; SE, 0.17; worry mean = 1.93; SE, 0.04), but again the interactions with deprivation were not significant (see Figures 4 and 5). Again, all significant results had small effect sizes and the mean change in anxiety and worry from before to after screening was small across all levels of deprivation (see Table 3).[3]

[3] A series of further analyses collapsing both the Townsend index and the individual level-marker to three category systems were carried out and did not reveal any further significant associations.

Figure 4 - Change in anxiety from before to after screening by socioeconomic deprivation (Individual-level).

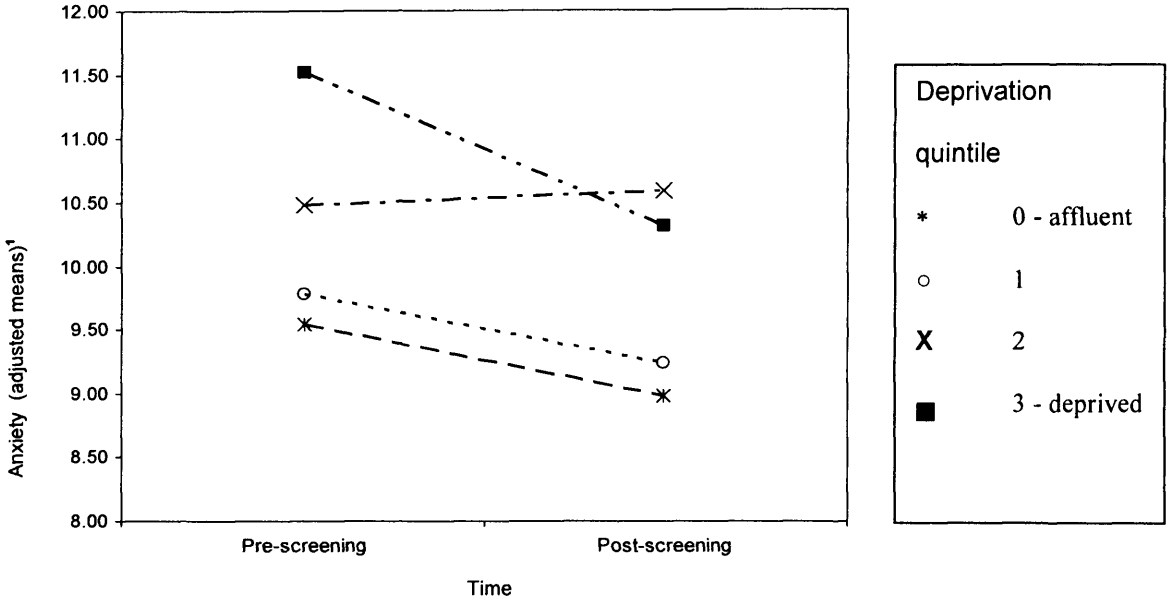


Figure 5 - Change in bowel cancer worry from before to after screening by socioeconomic deprivation (Individual-level).

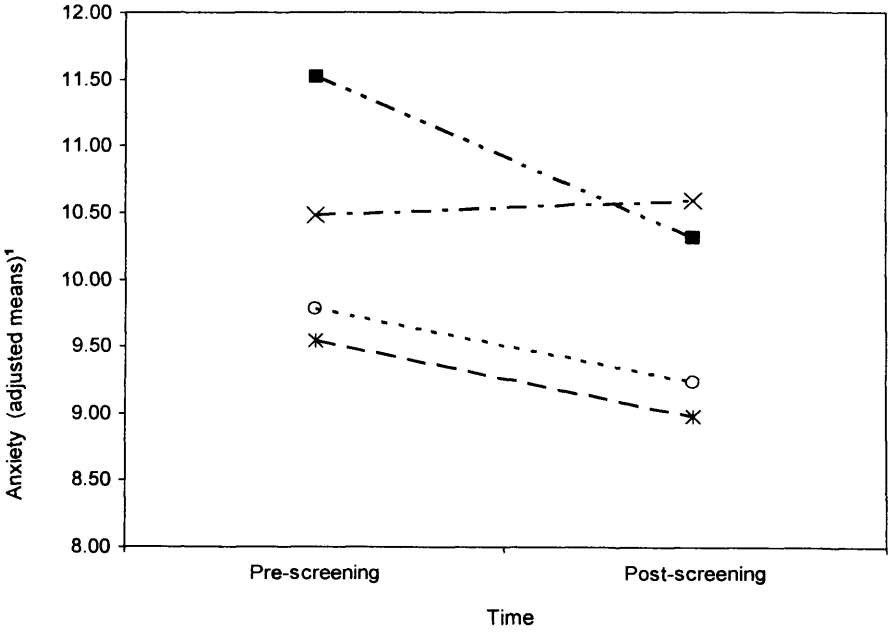


Table 3 Individual-level deprivation: Change in anxiety and worry about bowel cancer from before to after screening, controlling for screening outcome.

		Anxiety		Bowel cancer worry	
Individual-level deprivation		Mean change	95% CI	Mean change	95% CI
Affluent	0	-0.56	-0.88 to -0.24	-0.07	-0.14 to -0.01
	1	-0.55	-0.89 to -0.22	-0.16	-0.23 to -0.09
	2	0.11	-0.57 to -0.79	-0.15	-0.29 to -0.01
Deprived	3	-1.21	-2.30 to -0.11	-0.22	-0.45 to 0.00

Post-FS sample

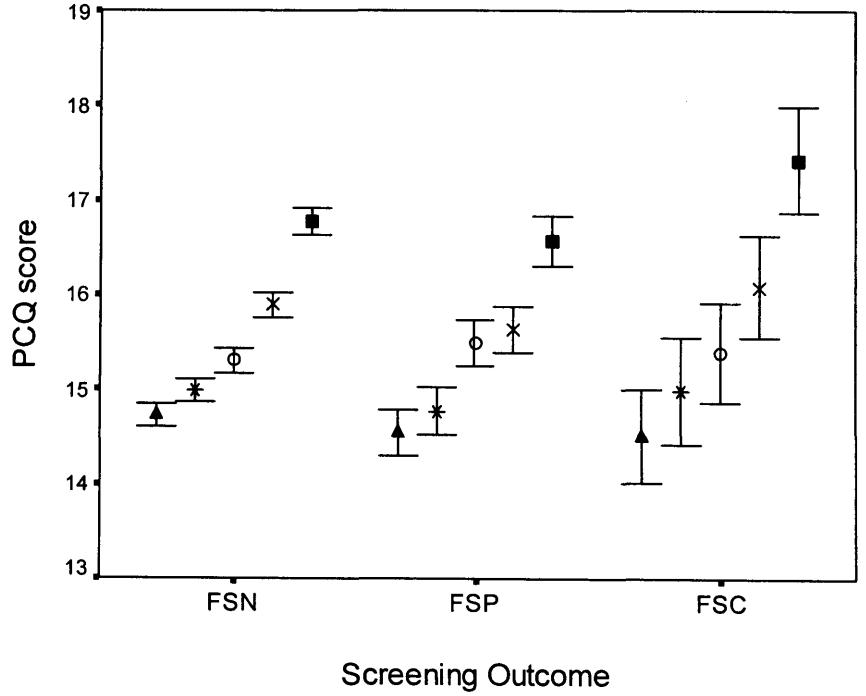
There were 140 cases of cancer identified via screening. These people were not asked to complete a 3-month post-FS questionnaire and were followed up separately. All other participants who attended screening (N = 40,534) were asked to complete a questionnaire. In these analyses, data from 2,897 Scottish participants and 358 participants from England and Wales, for whom the Townsend index scores were not available, were excluded. In addition, the data from the trial's two pilot centers: Leicester (N = 3,893) and Welwyn Garden City (N = 532) were excluded, since the clinical procedure was slightly different in these centres. The possible final sample size was therefore 32,854 of whom 29,804 (90.7%) completed a post-FS questionnaire. The FSC group were somewhat less likely to complete the questionnaire than the other two outcome groups (χ^2 = 63.58, df = 2, p<0.001) (86.2% vs 95.2%). Questionnaire completers were more affluent than non-completers as measured by the Townsend score (F [1, 32853] = 139.16, p<0.001). Men were slightly less likely to complete the questionnaire than women (χ^2 = 16.60, df = 1, p<0.001) (90.0% vs 91.3%) but there was no association with age.

The average age of participants was 60.5 years, with 14,876 women (49.9%) and 14,928 men (50.1%). Men were more likely than women to have a positive result (χ^2 = 697.95, df = 2, p<0.001) as expected from their higher incidence of bowel cancer. Participants who had polyp removal (FSP) or colonoscopy (FSC) were slightly older (60.60 vs 60.42 years) than those with an initially clear result (F [2, 32214] = 16.71, p<0.001). SES (Townsend Index) was also significantly related to screening outcome (χ^2 = 15.85, df = 1,

$p<0.01$). 21.8% of the most deprived group were referred for colonoscopy compared to only 19.6% in the most affluent group.

Scores on the STAI, GHQ and PCQ by SES and screening outcome are shown in Table 4. Overall, the levels of distress (GHQ) and anxiety (STAI) in this sample were low compared to other community and population samples (e.g. (Evans et al 2004, Marteau & Bekker 1992, Pevalin & Goldberg 2003)). Distress was not associated with SES, but there was a graded association between SES and anxiety (F [4, 28951] = 68.40 $p<0.001$, partial eta squared = 0.009). Ratings of positive consequences of screening (PCQ) were also linked to deprivation (F [4, 28997] = 195.91 $p<0.001$, partial eta squared = 0.026); but lower SES groups reported *more* positive consequences of screening (Figure 6).

Figure 6 – The relationship between PCQ scores in relation to screening outcome by quintile of socioeconomic deprivation.



Screening outcome was related to psychological well-being, but contrary to expectation, psychological well-being was highest in those who had the colonoscopy. This group had the lowest scores for anxiety (F [2, 28239] =10.38 p<0.001, partial eta squared = 0.001) and distress (F [2, 28239] = 10.38 p<0.001, partial eta squared = 0.001). There were no differences in positive consequences scores (F [2, 29311] =2.39, NS) between the outcome groups.

Interactions between SES and outcome group were not significant for any of the psychological variables: (STAI F [8, 28952] = 1.35, p = 0.21, PCQ F [8, 28998] = 1.50, p = 0.15, GHQ F [8, 27940] = 1.42, p = 0.18).

Table 4 The relationship between SES, screening outcome and psychological well-being at the post-screening assessment, controlling for age and gender.

		Mean (95% CI)		
Screening outcome group	Area-level Deprivation (Townsend)	GHQ	PCQ	Anxiety
FSN (Negative)	1	8.82 (8.72-8.92)	14.72 (14.58-14.85)	9.41 (9.29-9.52)
	2	8.75 (8.65-8.85)	14.99 (14.85-15.12)	9.58 (9.46-9.69)
	3	8.83 (8.73-8.93)	15.30 (15.16-15.43)	9.71 (9.59-9.82)
	4	8.75 (8.63-8.84)	15.89 (15.76-16.03)	9.95 (9.84-10.07)
	5	8.81 (8.70-8.91)	16.76 (16.62-16.89)	10.57 (10.45-10.68)
FSP (Lower risk polyps)	1	8.67 (8.47-8.86)	14.57 (14.32-14.82)	9.42 (9.20-9.63)
	2	8.71 (8.52-8.90)	14.76 (14.52-15.01)	9.69 (9.48-9.60)
	3	8.81 (8.62-9.00)	15.50 (15.25-15.74)	9.89 (9.68-10.10)
	4	8.74 (8.55-8.93)	15.66 (15.42-15.90)	10.16 (9.95-10.37)
	5	7.96 (7.56-8.36)	16.58 (16.33-16.84)	10.38 (10.17-10.60)
FSC (Colonoscopy)	1	8.44 (8.02-8.85)	14.51 (13.98-15.04)	9.09 (9.63-9.54)
	2	8.42 (8.01-8.84)	14.99 (14.44-15.53)	9.13 (8.66-9.60)
	3	8.20 (7.77-8.62)	15.39 (14.84-15.95)	9.33 (8.85-9.81)
	4	8.75 (8.36-9.15)	16.08 (15.56-16.60)	9.29 (8.84-9.73)
	5	7.96 (7.56-8.36)	17.42 (16.90-17.94)	9.61 (9.16-10.05)

Discussion

This aim of this study was to test the hypothesis that there would be an association between SES and emotional reactions to a novel stressful experience, bowel cancer screening. Anxiety was higher in lower SES groups both before and after screening, reflecting established differences in psychological well-being found in general population studies (Hollingshead & Redlich 1958, Lorant et al 2003). Worry about cancer was also higher, which was reported in the Glasgow centre of the FS Trial (Wardle et al 2004), but this is not an issue that has been examined widely. The sample sizes for both the longitudinal data and the post-FS sample were large meaning that there was adequate power to detect small effect sizes. All of the significant effects were small, but these results were important because there is still a general assumption in the screening literature that people will experience *increased* distress as a result of screening. These results challenge this assumption by showing that people can experience small, but significant, reductions in anxiety and worry about cancer after screening has taken place. The participants in this trial clearly did not find the screening experience distressing.

There was little evidence that lower SES groups had more negative reactions to screening. The hypothesis that lower SES groups would have additional emotional vulnerability in response to a moderately stressful medical procedure did not appear to be supported. This finding was consistent using both the area-level and individual-level indicators of SES. The Townsend index was divided into quintiles and was a measure of relative deprivation within the sample whereas the individual-level indicator measured absolute levels of deprivation. There were no differences in reporting either of significant results or of the magnitude of the effect using the two different markers.

Similar to the findings from other research studies, the two deprivation measures were significantly correlated, but at a lower level than might be expected. This implies either that the two measures assess different aspects of SES or that one measure is more accurate than the other. It is not possible to come to a definitive conclusion about this, but given the similarlity of the results using the two measures, I think that either could be useful. The Townsend Index could be used in this study based on data from the 1991 census as the data collection period was between 1994 and 1999. The remaining studies in this thesis use new data with collection since 2001, and therefore since the new census data has become available. Problems with using the new census data, as discussed in Chapter 4, mean the Townsend Index may be less relevant as it is now based on larger area statistics.

Returning to the results from this study, I anticipated that the sub-set of participants referred for colonoscopic examination would experience greater stress because of the additional medical investigation and the greater delay before receiving a clear result, and expected that this would create relatively more distress in the lower SES groups. The post-FS sample provided an adequate sample size to explore SES differences by screening outcome. Overall the levels of distress and anxiety were low post-screening. More importantly, they were lower for the two outcome groups who had more pathology detected (FSP and FSC outcomes). People referred for colonoscopy also reported the most positive consequences of taking the test. One possible explanation is that people who had a colonoscopy experienced the greatest 'relief' when the results were received. If relief is positively valued, then it might, at least transiently, give the best outcome. Results from other screening studies have also shown that on receipt of a negative test there can be an

immediate decrease in distress, again defined in terms of relief because the threatening situation is positively resolved (Essink-Bot et al 1998, Parker et al 2002, Scaf-Klomp et al 1997). Contrary to my prediction, lower SES groups were not any more adversely affected by being referred for colonoscopy. This gives no support to the idea that low SES groups have an impaired capacity to respond to new difficulties (Kristenson et al 2004), at least in terms of their psychological health. It is possible that lower SES participants benefited to a greater extent from the additional attention and health information provided at the time of colonoscopy than did others.

Across the groups as a whole, lower SES was associated with identifying more positive psychological consequences of taking the test, despite having higher levels of anxiety and worry about cancer. Previous research has shown that individuals may simultaneously feel distress and well-being (Schroevers et al 2000, Watson & Clark 1997) but the extent to which demographic and health status outcomes relate to levels of positive experiences has not been fully explored. One recent study found that 'benefit-finding' increased with more severe disease stage, lower SES and higher negative affect in women with breast cancer (Tomich & Helgeson 2004). The authors argued that the more severe the threat, the greater the need to mobilize resources to minimize its impact, and finding benefit in the experience is one way of doing this. If lower SES groups typically experience higher levels of life stress, they may have more experience of using this strategy to minimize impact. Supporting evidence for this is that individuals who experience more traumatic life events report more benefits than those who experience fewer traumas (Cordova et al 2001, McFarland & Alvaro 2000).

The results did not appear to support my original hypotheses regarding psychological reactions to stress in low SES groups raising the possibility that the conditions in which the hypotheses were tested were not satisfactory. A limitation of the study design was that only people who had expressed an interest in the test were subsequently invited to take part in the trial. This introduced a bias in the selection of the participants according to SES. Higher SES participants were more likely to express an interest in taking the FS test and so were more likely to be invited to take part (McCaffery et al 2001) and also more likely to attend (Sutton et al 2000). This same bias is seen in all national screening programmes as well as in countries that use opportunistic screening (Fong Chiu 2003, Schootman et al 2003). However, it's not clear that this SES gradient in participation should explain why the lower SES groups had a more positive reaction to the test.

A second limitation is that the timing of the post-FS survey may have been too long after the screening took place and any transient differences in reactions to the test may have subsided during the 3 months after the test. But in the colonoscopy group, follow-up was only 4-6 weeks after the result on average, and less in some groups. In addition, all participants in the study had low levels of distress at follow-up. This could be because trial situations introduce a "Hawthorne effect" whereby clinic staff provide greater reassurance and information than would be usual outside of a trial setting. A review of this effect found only limited evidence in support of this idea (Braunholtz et al 2001). The low levels of distress also suggest that the stress experienced by people was not severe enough to allow any differences by SES to be displayed. There is increasing evidence that a clear screening test, even if more than one investigation is required before the all-clear, is a positive experience for some

people; perhaps as a reprieve from persistent worry, or in terms of relief after the stress of the procedure, as previously discussed. Future studies should address these limitations by choosing a situation that is both non-voluntary and highly stressful.

This research is important despite these limitations. It shows that, of the people who do come to take these tests, low SES participants experience a reduction in distress similar in magnitude to high SES participants, and may even perceive more positive consequences of participating in screening. There is no reason to think that the same would not be true for similar routine screening situations. This study demonstrates that despite expectations, lower SES groups were able to gain as much, if not more, psychological benefit from undergoing screening as more privileged groups. Few studies have examined SES differences in psychological reactions to stressors. These results suggest that low SES groups may be more resilient to novel stressors than previously expected (Taylor 1998). The subsequent studies of this thesis aim to pursue this idea and discover whether these findings are consistent across different situations.

CHAPTER 6

Study 2: Socioeconomic status and psychosocial outcomes in bowel cancer patients[4]

Introduction

The results from Study 1 indicated that there were no SES differences in psychological adjustment to bowel cancer screening. The screening did not appear to be a particularly stressful experience for the majority of participants. Psychological differences by SES in adjustment to medical stressors may only occur during more extremely stressful encounters. This study will explore reactions to a much more serious stressor, i.e. being diagnosed with colorectal cancer.

As discussed in Chapter 2, receiving a cancer diagnosis represents a major psychological challenge that can lead to increased symptoms of depression and anxiety and impaired quality of life. Being diagnosed with cancer also impacts on relationships with family and friends and consequently on the levels of social support the person receives during their illness. New relationships with medical staff have to be formed and the quality of these relationships is likely to be another significant factor in coping with the disease. Cancer and its treatments can also impose a variety of physical and functional disabilities which in turn can affect the patient's ability to work or to maintain independence.

As in the previous study, I will test the hypothesis that SES will interact with characteristics of the stressful situation and result in more adverse

[4] Parts of this chapter have been submitted for publication to *Psychooncology* and a copy is included in Appendix VI.

psychosocial outcomes for those from more deprived backgrounds. Study 1 examined differences in psychological adjustment over time and interactions with screening outcomes. In this study, I propose to cross-sectionally examine SES interactions with characteristics of the cancer diagnosis. I propose that disease stage at diagnosis is a factor that might affect psychological adjustment, although research findings have been inconsistent (also discussed in Chapter 2).

The present study examines the impact of disease stage and SES on emotional, social, physical and functional outcomes in colorectal cancer patients. A recent systematic review of research into social disparities in colorectal cancer patients concluded that there is still a lack of studies that explore the links between disparities and quality-of-life outcomes (Palmer & Schneider 2005). I hypothesized that people with lower SES and more advanced disease would experience more psychosocial problems, and that the greater threat of an advanced stage diagnosis would widen the difference in adjustment between low and high SES patients.

Hypotheses

1. Lower SES patients with a diagnosis of colorectal cancer will have worse emotional, social, physical and functional outcomes.
2. Patients with a diagnosis of more advanced colorectal cancer disease stage will have worse emotional, social, physical and functional outcomes.
3. There will be an interaction between SES and disease stage on psychosocial outcomes such that low SES patients with advanced disease will have worse emotional, social, physical and functional outcomes than higher SES patients with equivalent disease stage.

Method

Participants

This was a survey of all patients who had received a diagnosis of colorectal cancer at a single hospital in Southern England over a one-year period (July 2002-July 2003). 290 patients with colorectal cancer attended the participating hospital over the trial period, of which 231 were alive at the time of the survey. Patients' GPs were contacted one month prior to the survey so that they could exclude their patients if they were too ill to participate; this resulted in 19 exclusions. 212 patients were therefore sent a postal questionnaire. 95 (45%) initially returned a completed questionnaire. A further 11 patients declined participation, citing reasons ranging from feeling too unwell to feeling too well and not wanting to be reminded about cancer. After one month non-responders were contacted again and a further 33 patients sent back a completed questionnaire. In total 128/212 (60.4%) people completed and returned the questionnaire.

Design and Procedure

This was a cross-sectional survey sampling all new cases of colorectal cancer seen at the participating hospital during the trial period. Potential participants were identified via the hospital database. Patients were sent an introductory letter, patient information sheet, questionnaire and freepost envelope. The patient information sheet and questionnaire contained the contact details of a researcher. Potential participants were invited to contact the researcher with any questions regarding the study. Hospital staff sent out questionnaire packs which were returned anonymously to the research staff.

Questionnaires were numbered and linked to details in the hospital database to allow the hospital staff to send a reminder to non-responders after a month. Return of the questionnaire was taken as an indication of consent to participate in the questionnaire phase of the research. Additional formal consent was sought for access to the patient's medical records. Returned questionnaires were numbered and not named so that data returned to UCL was anonymous. Participants completed a self-report questionnaire on quality of life, social problems, experience of medical care, social support, anxiety and depression. Demographic information included ethnicity, gender, and socio-economic status (SES) (see Appendix VII).

Ethical approval was obtained from the Isle of Wight, Portsmouth and South East Hampshire Local Research Ethics Committee (see Appendix VIII).

Measures

Socio-economic status

Socio-economic status (SES) was indexed using the same individual-level indicator described in Study 1. Three items reflecting material circumstances and education were assessed: car-ownership or not (score 0/1), home-ownership or not, and some higher education versus none. This resulted in a composite score from 0 to 3, with '3' representing the highest deprivation. There were very few participants in the most deprived category (N = 8), so, for the purpose of analyses, this category was combined with the next level of deprivation. This resulted in three categories of socio-economic deprivation: affluent (score 0), medium (score 1) and high deprivation (score 2-3) (car-owner, home-owner and higher education).

Disease Stage

Disease stage was measured using the Duke's classification system with data taken from patient's medical records. A: the tumour penetrates the mucosa of the bowel wall but no further. B: the tumour penetrates into and/or through the muscular layer of the bowel wall. C1: the tumour penetrates into, but not through, the muscular layer of the bowel wall and there is evidence of colon cancer in the lymph nodes. C2: the tumour penetrates through the muscular layer of the bowel wall and there is evidence of colon cancer in the lymph nodes. D: the cancer has spread throughout the body and there are distant metastases e.g. in the liver or lung.

Quality of Life

Quality of life was assessed using the Functional Assessment of Cancer Therapy Colorectal version (FACT-C) (Ward et al 1999). This has five subscales: physical (7 items, e.g. 'I have pain'), functional (7 items, e.g. ' I am able to enjoy the things I usually do for fun'), social/family (7 items, e.g. 'I get emotional support from my family), emotional well-being (6 items e.g. 'I feel nervous') and a colorectal-specific subscale (7 items e.g. 'I have control of my bowels'). Participants indicate how true each statement is for them during the past seven days. There are five response options from 'not at all' to 'very much'. The scale range is 0 to 24 for the 6-item scale and 0 to 28 for the 7-item scales, with higher scores indicating better quality of life. A total score is computed from the sum of the physical, functional, social/family and emotional subscales, with a range from 0 to 108. The FACT-C has good internal reliability (overall: $\alpha = 0.91$, subscales: α range = 0.71-0.88) and an ability to distinguish between groups based on their functional status and extent of disease (Ward et al 1999).

Social Support

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al 1988). The MSPSS is a measure of the subjective assessment of social support adequacy. It is a 12-item scale with three subscales (4 items each) examining support from family (e.g. 'my family really tries to help me'), friends (e.g. 'I can count on my friends when things go wrong'), and significant other (e.g. 'There is a special person who is around when I am in need'). Participants are asked how much they agree or disagree with each statement. A five-point response rating scale was used from 'strongly disagree' to 'strongly agree'. The scale range is 1 to 60 with higher scores indicating better support.

Social Difficulties

The Social Difficulties Inventory (SPI) (Wright et al 2005) is a 21-item questionnaire designed for use in oncology care. It covers problems in managing personal care, domestic chores and responsibilities, finances and benefits, employment, relationships, sexuality and body image, mobility and leisure activities. Participants rate whether they have experienced any difficulties over the past month. There are four response options with a range from 'no difficulty' to 'very much'. Participants mark the 'no difficulty' box if the question does not apply to them. The scale range is 0 to 63 with higher scores indicating more social problems.

Medical Interactions

Communication with medical staff was assessed using the 4-item subscale from the Cancer Evaluation and Rehabilitation System – Short Form (CARES-SF) (Schag CA & Heinrich RL 1988). The items refer to levels of information provided, understanding the information provided, levels of control over treatment, and difficulty asking questions. Participants are asked how

much each statement applies to them during the past month (Schag CA & Heinrich RL 1988). For example: 'I find that the medical team withholds information from me about the cancer'. There are five response options from 'not at all' to 'very much'. Items are summed and divided by the number of items answered, resulting in a scale from 0 to 4. Higher scores indicate poorer communication with medical staff.

Psychological Well-being

Depression was measured with the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff LS 1977). This scale asks about feelings over the past week and the number of days that they felt that way. For example: "I was bothered by things that don't usually bother me" with response options from 'rarely, none of the time (less than one day)', to 'most or all of the time (5-7 days)'. The shorter 10-item version (Kohout et al 1993) was used, but retained the original response options. The CES-D is scored 0-3. Items are summed to form a scale that ranges from 0 to 30 with higher scores indicating more depression.

Anxiety was assessed using the Hospital Anxiety and Depression Scale (HADS) anxiety scale (HADS-A, 7 items) (Zigmond & Snaith 1983). Participants rate how they have usually felt over the past week. For example 'worrying thoughts go through my mind' with the response options 'a great deal of the time, 'a lot of the time', 'from time to time but not too often' and 'only occasionally'. Each item has four response options that vary slightly according to the statement. Positively worded statements (e.g. 'I can sit at ease and feel relaxed) are reversed scored. Items are scored 0 to 3 and summed to form a scale ranging from 0 to 21, with higher scores indicating more anxiety.

Analyses

Data were analyzed using analysis of variance with SES group and disease stage as the independent variables, and age as a control variable. Missing data on individual items were replaced using the subject mean for each subscale if at least half of the items had been completed (Fairclough DL & Cella 1996).

I hypothesized that lower SES and more advanced disease would be associated with poorer outcomes. I also hypothesized that the worst prognoses (Dukes stage C2, D and those receiving palliative care) would be particularly stressful for lower SES participants, and so I predicted a disease stage by SES interaction.

Results

128/212 (60.4%) questionnaires were returned. Table 1 shows the demographic and medical characteristics of the sample. Participants were 52% male (N = 65) and 48% female (N = 60) (missing: n = 3). 100% were white. Their mean age was 70.2 (SD = 10.7), with a range from 36 to 89. The breakdown of the socio-economic markers showed that there was a roughly equal distribution of participants with (42.2%) and without (46.1%) educational qualifications. 74.2% of the sample were car owners, which was slightly lower than the national ownership figures (77% (Rickards et al 2004)) whereas home ownership (75% of the sample) was somewhat higher than national figures (69% (Rickards et al 2004)). There were no differences between responders and non-responders in terms of either age, gender or residential area deprivation (Townsend Index, Townsend et al 1988).

Disease stage was indexed using the Duke's classification system with data taken from patient's medical records. Disease stage information was available for 86% (N = 110) of participants. 10 participants did not give consent for their medical records to be examined. A further 8 patients were excluded from the analyses. Staging information was not obtained for two patients that declined treatment and one patient who did not have surgery due to the presence of another co-morbid condition. A further four patients were excluded because they had anal squamous cancers and one patient was excluded because the diagnosis was appendiceal cancer. The majority of participants (54.7%) had a Dukes stage B or C1 diagnosis (Table 1). 11 (8.6%) participants had a Dukes D stage or were receiving palliative care and 12 (9.4%) participants had a Dukes C2 diagnosis; these two categories were combined to form one advanced stage category in the subsequent analyses. Neither age nor gender were related to disease stage.

Lower SES participants were older (F (1,103) = 12.34 p<0.001) and more were female (χ^2 = 4.24, df = 1, p<0.05). The average time between diagnosis and completing the questionnaire was 257 days (SD = 112 days). Time since diagnosis was not related to either disease stage or SES.

Patients with more advanced disease had poorer quality of life for all except one of the FACT-C subscales (see Table 2). They had worse physical well-being (F (1,108) = 3.74 p <0.01), functional well-being (F (1,109) = 3.67 p<0.01), emotional well-being (F (1,109) = 3.73 p<0.01), and colorectal symptoms (F (1,110) = 2.67 p<0.01), and a much lower overall score (F (1,108) = 5.71 p<0.001). The only scale that did not show differences was the

Table 1 Demographic and medical characteristics

		N *(N = 128)*	%
Disease stage	A	17	13.3
	B	41	32.0
	C1	29	22.7
	C2	12	9.4
	D and palliative	11	8.6
	Exclusions and refusals	18	14.1
Gender	Male	65	50.8
	Female	60	46.9
	Missing	3	2.3
Education	No formal qualifications	59	46.1
	Some formal qualifications	54	42.2
	Missing	15	11.7
Car owner	None	29	22.7
	One	70	54.7
	More than one	25	19.5
	Missing	4	3.1
Home owner	Own	96	75.0
	Rent	20	15.6
	Other	9	7.1
	Missing	3	2.3

social/family subscale. More advanced disease stage was related to the perception of receiving less social support (overall MSPSS score: F (1,107) = 2.57 p <0.05) particularly from 'significant others' (F (1,106) = 2.86 p<0.01) but there was no difference in support received from friends. Patients with more advanced disease were also more anxious (F (1,108) = 3.32 p<0.01) and depressed (F (1,108) = 6.92 p<0.001) and experienced more social problems (F (1,109) = 2.674 p<0.05). Quality of medical interactions did not significantly differ by disease stage. The partial eta squared statistic (Table 2) indicated that the effect sizes ranged from small (from 0.01 to 0.08) to medium (from 0.09 to 0.24) derived by squaring Cohen's r criteria for small, medium and large effect sizes (Cohen 1988).

SES was related to the overall quality of life score (F (1,101) = 3.58 p<0.01) and the physical well-being subscale (F (1,101) = 2.99 p<0.05) with the lower SES participants having less physical ability and worse overall quality of life (Table 3). Low SES participants also perceived that they had less social support (MSPSS total score: F (1,01) = 2.48 p<0.05), particularly from family members (F (1,100) = 2.86 p<0.05) and significant others (F (1,100) = 2.92 p<0.05), although there was no difference in support from friends. Lower SES was also associated with higher anxiety (F (1,102) = 3.88 p<0.01) and depression (F (1,102) = 4.03 p<0.01). Low SES groups reported the least satisfaction with medical staff interactions (F (1,103) = 5.13 p<0.01), and the highest level of social problems (F (1,102) = 4.24 p<0.01). Again the partial eta squared statistic showed effect sizes in the small to medium range (Table 3).

There were significant interactions between SES and disease stage for anxiety (Figure 1A) (F (6,102) = 2.63, p<0.05), and perceived social support from families (Figure 1B) (F (6,100) = 2.63, p<0.05) (See Table 4 for Means and

Table 2 The relationships between psychosocial resources, quality of life, psychological distress and disease stage, controlling for age

Dependent Variables	Disease Stage - Mean (95% CI)				Linear Univariate ANOVA P-value	Partial eta squared
	A (n = 17)	B (n = 41)	C1 (n = 29)	C2/D/Palliative (n = 23)		
Quality of Life						
Physical	24.9 (22.6-27.2)	24.7 (23.3-26.2)	22.9 (21.1-24.8)	20.9 (18.9-23.0)	P = 0.005	0.039
Functional	22.0 (19.1-25.0)	21.3 (19.4-23.2)	19.6 (16.7-21.4)	16.7 (14.1-19.2)	P = 0.003	0.088
Emotional	20.2 (17.9-22.4)	20.4 (19.0-21.9)	18.8 (17.1-20.6)	16.5 (14.6-18.5)	P = 0.008	0.063
Social/Family	21.3 (18.7-23.9)	23.2 (21.5-24.8)	19.9 (17.8-21.9)	20.7 (18.5-22.9)	P = 0.367	0.097
Colorectal	22.2 (19.6-24.8)	21.2 (19.5-22.9)	20.0 (18.0-22.1)	17.8 (15.5-20.1)	P = 0.009	0.126
Overall	88.3 (81.1-95.6)	89.6 (84.9-94.2)	80.4 (74.6-86.2)	74.8 (68.5-81.0)	P = 0.001	0.124
Social Support						
Family	18.5 (16.8-20.1)	18.4 (17.4-19.4)	16.7 (15.7-18.0)	17.2 (15.9-18.5)	P = 0.104	0.059
Friends	17.3 (15.7-18.8)	17.6 (16.6-18.5)	16.3 (15.1-17.5)	16.0 (14.7-17.4)	P = 0.108	0.052
Significant Other	19.1 (17.6-20.6)	18.8 (17.9-19.8)	17.8 (16.7-18.9)	16.8 (15.6-18.1)	P = 0.011	0.126
Overall	54.8 (50.8-58.8)	54.7 (52.2-57.2)	50.9 (47.8-53.9)	50.0 (46.7-53.3)	P = 0.026	0.092
Psychological Distress						
Anxiety	2.8 (0.9-4.7)	3.2 (2.0-4.4)	4.1 (2.7-5.6)	6.1 (4.5-7.6)	P = 0.007	0.052
Depression	2.7 (0.3-5.1)	4.7 (3.2-6.2)	6.4 (4.6-8.2)	9.4 (7.3-11.4)	P = 0.000	0.163
Medical Interactions	0.3 (0.0-0.6)	0.2 (0.0-0.4)	0.3 (0.1-0.6)	0.6 (0.3-0.8)	P = 0.189	0.036
Social Difficulties	5.3 (2.0-8.8)	5.4 (3.2-7.6)	9.0 (6.4-11.7)	9.4 (6.5-12.3)	P = 0.026	0.065

Table 3 The relationships between psychosocial resources, quality of life, psychological distress and socio-economic deprivation, controlling for age

Dependent Variables	Socio-economic deprivation - Mean (95% CI)			Linear Univariate ANOVA P-value	Partial eta squared
	Affluent (n = 42)	Medium (n = 46)	Deprived (n = 28)		
Quality of Life					
Physical	25.0 (23.2-26.7)	23.4 (21.7-25.0)	21.6 (19.5-23.7)	P = 0.017	0.071
Functional	20.7 (18.4-23.1)	20.3 (18.0-22.5)	17.1 (14.2-20.0)	P = 0.060	0.101
Emotional	19.8 (18.2-21.3)	19.5 (18.1-21.0)	17.9 (16.1-19.8)	P = 0.132	0.030
Social/Family	22.3 (20.3-24.4)	20.6 (18.6-22.6)	19.6 (17.0-22.1)	P = 0.104	0.056
Colorectal	21.8 (19.8-23.8)	20.6 (18.7-22.5)	18.9 (16.5-21.3)	P = 0.068	0.056
Overall	87.7 (82.4-93.1)	83.6 (78.3-88.8)	76.2 (69.6-82.8)	P = 0.009	0.128
Social Support					
Family	18.0 (17.0-19.0)	18.0 (17.0-19.0)	16.1 (14.8-17.5)	P = 0.036	0.059
Friends	16.8 (15.6-18.0)	16.7 (15.5-17.8)	16.2 (14.6-17.9)	P = 0.605	0.039
Significant Other	18.1 (17.0-19.1)	18.3 (17.3-19.3)	16.4 (15.1-17.7)	P = 0.050	0.035
Overall	52.8 (50.0-55.6)	53.0 (50.3-55.7)	48.4 (45.0-51.9)	P = 0.054	0.055
Psychological Distress					
Anxiety	2.7 (1.5-3.9)	4.3 (3.1-5.4)	5.2 (3.7-6.6)	P = 0.010	0.092
Depression	5.1 (3.3-6.9)	5.2 (3.5-6.9)	8.9 (6.6-11.1)	P = 0.011	0.113
Medical Interactions	0.1 (-0.1-0.3)	0.5 (0.3-0.7)	0.6 (0.3-0.8)	P = 0.004	0.135
Social Difficulties	5.0 (2.3-7.7)	6.4 (3.8-9.0)	11.1 (7.8-14.4)	P = 0.005	0.119

95% CI). Among high SES patients, anxiety remained low across all disease stages whereas lower SES participants with advanced disease had much higher levels of anxiety. Specifically, the significant difference lay between the deprived and affluent groups with a C2 or D diagnosis (Deprived group anxiety: M = 6.71, 95% CI = 4.47-8.96, vs Affluent group anxiety: M = 1.61, 95% CI = -0.99 – 4.20). For social support, the low SES participants with a C2 or D diagnosis experienced much less support, particularly from their families (Deprived group family social support: M = 13.86, 95% CI = 11.82-15.90 vs Medium group: M = 19.09, 95% CI = 17.07-21.12 and Affluent group: M = 18.65 95% CI = 16.23-21.01). Both interactions had effect sizes in the medium range (partial eta squared, anxiety = 0.123, familial social support = 0.116).

The interactions for the other psychosocial outcomes did not reach statistical significance, but the patterns were similar. Examples of these relationships are shown in Figures 1C to 1F. For example, the graph showing the relationship between SES, disease stage and medical interactions (Figure 1F) is comparable to the distribution seen in the anxiety graph in that it is the high SES participants who maintain good levels of communication across the disease stages while lower SES participants experience worse communication with higher disease stage. Although some of these graphs indicate a possible interaction between SES and disease stage in terms of psychosocial outcomes, the overlapping confidence intervals seen in Table 4 demonstrate that these relationships were not statistically significant.

Figure 1 – The relationships between socio-economic deprivation, disease stage and psychosocial outcomes

Figure 1A - Anxiety

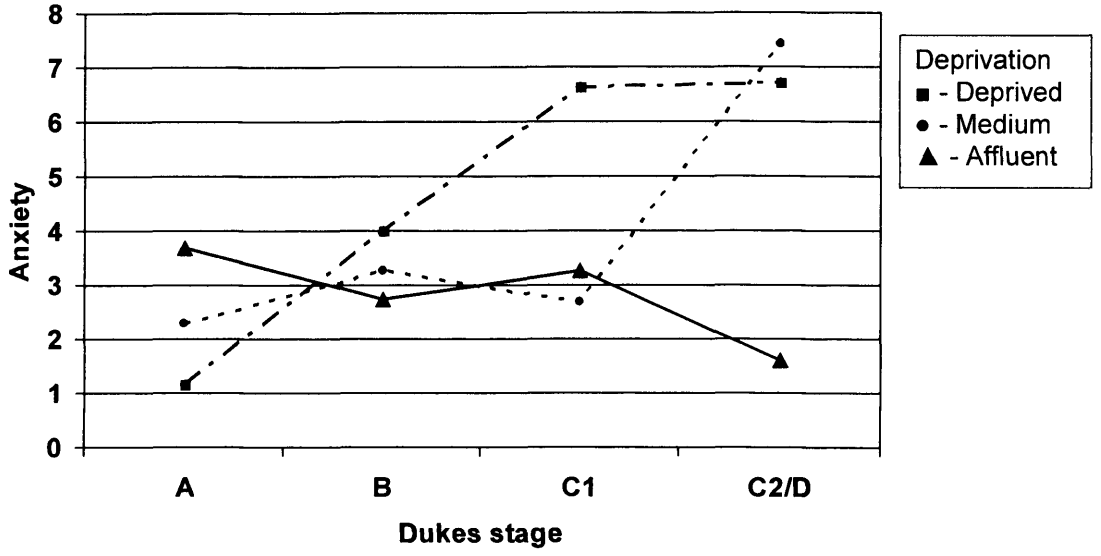


Figure 1B – Family Social Support

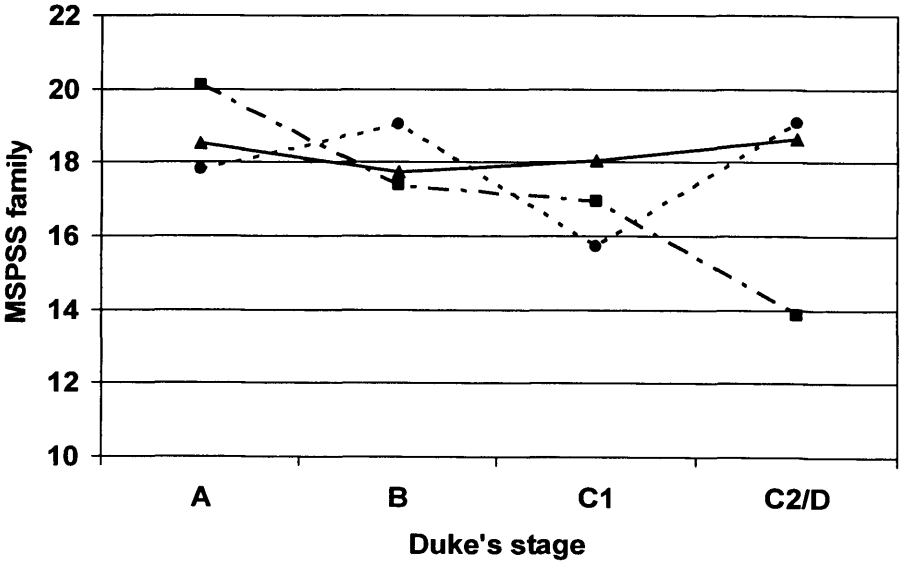


Figure 1C – Depression

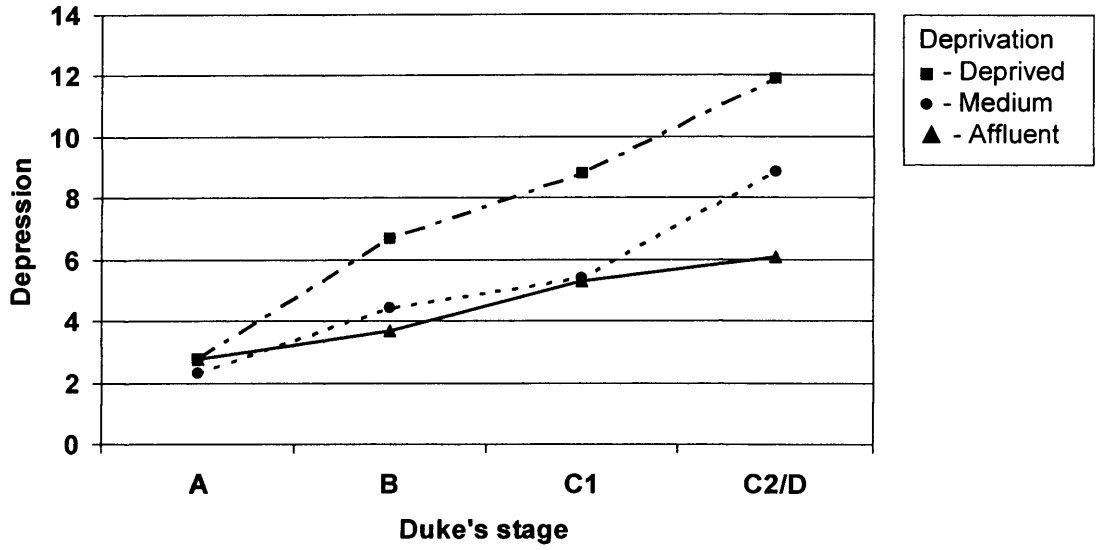


Figure 1D – Social Difficulties

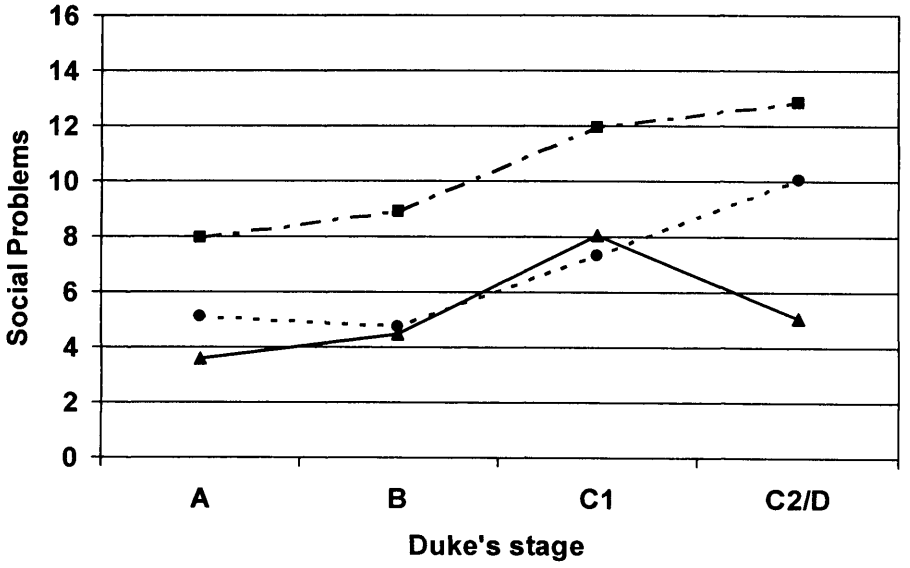


Figure 1E – Quality of Life

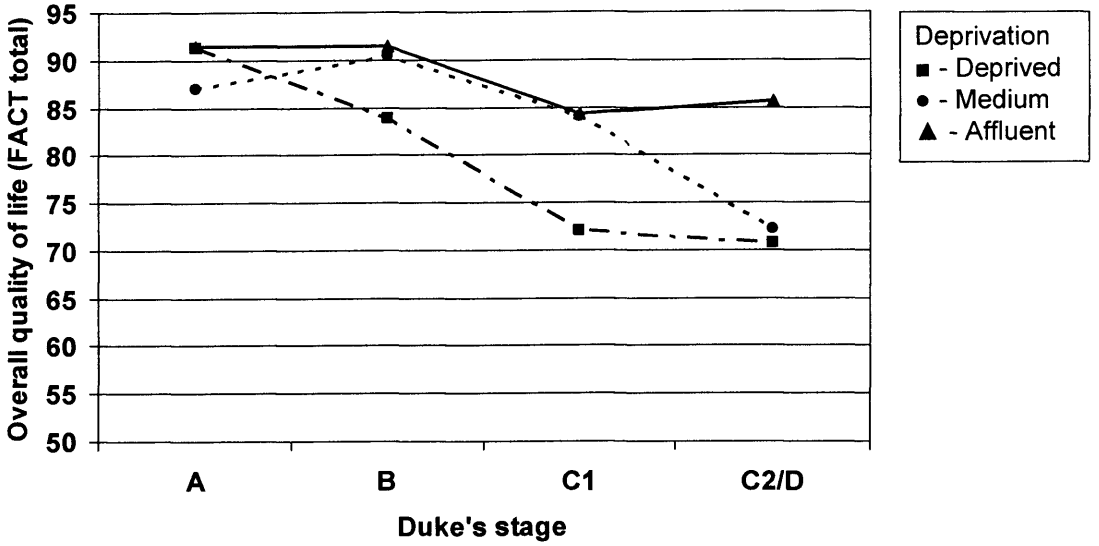


Figure 1F – Medical Interactions

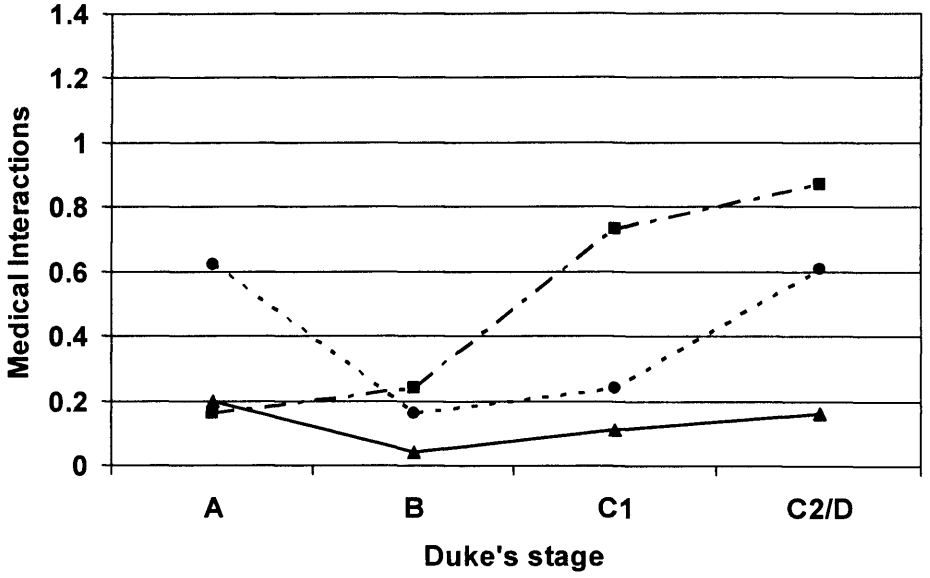


Table 4 Relationships between socio-economic deprivation, disease stage and psychosocial outcomes, controlling for age

Disease stage	Socio-economic deprivation	Dependent Variables - Mean (95%CI)					
		Anxiety	Familial Social Support	Depression	Social Difficulties	Quality of Life	Medical Interactions
A	Affluent	3.69 (1.44-5.93)	18.52 (16.49-20.56)	2.76 (-0.53-6.06)	3.58 (-1.28–0.84)	91.39 (81.29-101.50)	0.20 (-0.17-0.57)
	Medium	2.30 (-0.56-5.14)	17.83 (15.24-20.42)	2.32 (-1.87-6.50)	5.08 (-1.08-11.25)	86.99 (74.15-99.82)	0.62 (0.15-1.09)
	Deprived	1.15 (-2.51-4.81)	20.10 (16.04-24.15)	2.75 (-2.63-8.13)	7.96 (0.04-15.88)	91.28 (74.80-107.76)	0.16 (-0.44– 0.77)
B	Affluent	2.73 (0.98-4.48)	17.73 (16.14-19.32)	3.67 (1.10-6.25)	8.91 (3.22-14.60)	91.44 (83.55-99.33)	0.04 (-0.25-0.33)
	Medium	3.27 (1.78-4.76)	19.05 (17.70-20.41)	4.40 (2.20-6.59)	4.76 (1.53-7.98)	90.44 (83.73-97.16)	0.16 (-0.09-0.40)
	Deprived	4.01 (1.38-6.64)	17.40 (15.01-19.79)	6.67 (2.80-10.53)	4.46 (0.67-8.25)	83.87 (72.03-95.71)	0.24 (-0.20-0.67)
C1	Affluent	3.26 (1.46-5.06)	18.06 (16.43-19.69)	5.30 (2.67-7.94)	8.06 (4.18-11.95)	84.00 (73.94-94.05)	0.11 (-0.19-0.41)
	Medium	2.68 (0.57-4.79)	15.71 (13.68-17.73)	5.37 (2.27-8.46)	7.29 (2.46-12.12)	84.29 (76.19-92.38)	0.24 (-0.11-0.59)
	Deprived	6.63 (3.79-9.47)	16.95 (14.37-19.53)	8.78 (4.98-12.58)	11.93 (6.33-17.53)	72.11 (59.32-84.90)	0.73 (0.30-1.15)
C2/D/ Palliative	Affluent	1.61 (-0.99-4.20)	18.65 (16.29-21.01)	6.08 (2.26-9.89)	5.07 (-0.56-10.69)	85.71 (74.02-97.41)	0.16 (-0.27-0.59)
	Medium	7.41 (5.18-8.64)	19.09 (17.07-21.12)	8.86 (5.59-12.14)	10.06 (5.24-14.89)	72.20 (62.15-82.24)	0.61 (0.24-0.98)
	Deprived	6.71 (4.47-8.96)	13.86 (11.82-15.90)	11.90 (8.39-15.41)	12.83 (7.97-17.68)	70.71 (60.60-80.82)	0.87 (0.50-1.24)

Discussion

The aim of this study was to explore the relationships between disease stage, SES and psychosocial outcomes. I hypothesized that patients with low SES and more advanced disease would be at high-risk for poor psychosocial adjustment. I proposed that the increased stress of a more advanced cancer diagnosis would have a greater adverse impact on people with a low SES background compared to those with a high SES background.

The results of this study showed that more advanced disease was related to worse outcomes on almost every measure. The existing literature in this area focuses mainly on breast cancer patients and the conclusions are inconsistent; perhaps because patients with advanced disease are often examined separately (Pinder et al 1993) and not compared to patients with other diagnoses. It is also more difficult to recruit and retain patients with advanced disease (Bleiker et al 2000). In our study, patients with a C2 or D diagnosis had an incrementally larger difference in adjustment compared with the differences between the other stages. This highlights the importance of including patients with advanced disease in comparative research studies, where possible, and indicates that there are significant unmet psychosocial needs in this group of patients. Including patients with very advanced disease in research studies is not always feasible or appropriate, either for the patients or in terms of efficient research design. If those with more advanced disease stage are experiencing high levels of distress then involvement in psychological research may be too intrusive. Equally, within the context of smaller longitudinal studies, the high mortality associated with advanced disease could compromise the effectiveness of statistical analyses.

Lower SES was also associated with worse psychosocial outcomes across the board, with poorer psychological well-being, less social support, poorer quality-of-life, more social difficulties and less satisfaction with medical interactions. A relationship between SES and psychological well-being in cancer patients has been found in other studies (Dean 1987, Macleod et al 2004) but there is little literature that examines SES differences in the quality of communications with medical staff. Socio-economically deprived women reported receiving less information from a hospital specialist than more affluent women in a study of 177 breast cancer patients (Macleod et al 2004). Doctors have also been found to communicate better with people they perceive to be of the same social class as themselves (van Ryn & Fu 2003). Our data also show that low SES patients are less satisfied with their interactions with medical staff. The differences in ratings between SES groups although small represented a medium effect size. Training medical staff to communicate well with their patients is important (Fallowfield & Jenkins 2004) and one focus of this training should be on patients who are culturally, socially or economically different from the doctors or nurses themselves.

Lower SES patients also experienced more social problems across work, finances, relationship and physical functioning/mobility. A number of studies have reported increased social difficulties amongst cancer patients (Malone et al 1994, Taskila-Abrandt et al 2005), but few have also examined the impact of SES. One other study has shown that lower SES patients worry more about money and have more family problems (Macleod et al 2004), but this area is under-explored. The higher level of social problems in lower SES patients means that there is a greater challenge to psychological health.

Analyzing the interactions between SES and disease stage provided some evidence that the gap in adjustment between higher and lower SES groups widens with increasing disease stage. Higher SES patients reported lower levels of anxiety regardless of their disease stage, whereas lower SES patients with higher disease stage had higher anxiety. This interaction suggests a protective effect of being in a high SES group. For social support, the low SES patients experienced far less support, particularly from their family, when they had a C2/D diagnosis compared to higher SES patients. Levels of social support for other disease stages were comparable across SES groups. Although levels of both anxiety and social support are socially distributed throughout the general population (Mickelson & Kubzansky 2003, Office for National Statistics 2000) these findings demonstrate that these SES differences are exacerbated in a situation of severe stress, in this case, by being diagnosed with advanced stage cancer.

These findings complement the study by Janz et al (2005) which showed that treatments (particularly chemotherapy) can also have a substantially worse impact, in terms of quality of life, in patients with less education. These results support the hypotheses of this study and are in contrast to the null findings of Study 1. This suggests that SES differentials in adjustment to medical stressors may only be important during the most stressful circumstances. A detailed comparison between the results of Study 1 and this study cannot be achieved because different measures of psychological adjustment were used in each case.

This study contributes to an initial picture of how lower SES can adversely affect psychological reactions to different medical stressors, but there are limitations to the study. The sample size was relatively small, and like other

studies, there were difficulties recruiting participants with advanced disease (C2: n =12; D or palliative: n = 11). The response rate was only moderate (60.4%), although there were no differences between responders and non-responders in terms of age, gender or residential area deprivation. These results must be considered preliminary and there is a need to replicate the results. A longitudinal research design would also give better data on SES differences in adjustment over time. However, the message from these results is that the psychosocial burden of colorectal cancer is significantly greater in those with more advanced disease and greatest among patients whose material and educational backgrounds make it more difficult to cope with this additional stress. Fortunately, there is some evidence that low SES groups with cancer respond well to interventions to improve quality of life (McEvoy & McCorkle 1990, Taylor et al 2003), suggesting that provision of extra support services could have a beneficial effect. This study also contributes to our understanding of individual differences in reactions to cancer-related stressors. These results further our knowledge of how SES can affect reactions to stress leading to better awareness of the ways in which inequalities in psychological health arise.

CHAPTER 7

Study 3: Qualitative investigation of educational differences in colorectal cancer patients' experiences of oncology care

Introduction

Satisfaction with care in oncology is a key goal in terms of delivery of services and an important area of research. Medical staff can be trained to improve their performance (Fallowfield et al 2003) and understanding the factors that influence patient satisfaction can help to target these training interventions. This topic is discussed in more detail in Chapter 2. In Study 2, I assessed satisfaction with care in a sample of 128 colorectal cancer patients and found that lower SES was related to slightly less satisfaction with interactions with medical staff and there was a medium effect size. However, the survey method employed in Study 2 did not explore this issue fully. Lower SES participants could have found it harder to complete the survey because of lower health literacy (Davis et al 2002), and important dimensions of (dis)satisfaction could have been missed using the survey method. Qualitative interviews to explore these issues will help to provide a basis for developing appropriate research tools and identifying issues for future quantitative studies.

Arguably, qualitative interviews could be more effective at revealing dissatisfaction than quantitative surveys because they set no limits to the domains of dissatisfaction and allow patients to answer in their own terms. Qualitative research may also have particular clinical relevance because its descriptive ability imparts greater awareness of the social dynamics of medical encounters to the

reader. Physicians who read qualitative research studies can identify with the situations described and use the results to negotiate similar social settings (Giacomini & Cook 2000).

None of the qualitative studies looking at patient satisfaction discussed in Chapter 2 have specifically addressed socio-economic status (SES) differences in satisfaction. The current study uses a qualitative approach to explore cancer patients' experiences with medical care. Supplementary quantitative information was also obtained to examine the correspondence between the two methods. Colorectal cancer patients provided a mixed-gender sample, and purposive sampling according to neighbourhood characteristics ensured inclusion of participants from a wide range of social backgrounds.

Aims

This is an exploratory qualitative study and, as such, there are no set hypotheses. The aims of the study are:

1. To examine colorectal cancer patients' experiences and satisfaction with medical care.
2. To examine the reasons given for patient (dis)satisfaction.
3. To compare levels of satisfaction between patients with high and low levels of further education.
4. To compare survey and interview methods as a means of collecting information about patient (dis)satisfaction.

Method

Using qualitative and quantitative methods

Qualitative and quantitative research have traditionally been considered mutually exclusive methodologies due to their differing epistemological stances i.e. constructivist versus realist. This boundary has become considerably blurred in recent years with researchers from both traditions acknowledging the utility of different research methods (Foss & Ellefsen 2002, Malterud 2001, Sandelowski 2000). I am using a qualitative method in addition to a quantitative method in this study in order to gain a better understanding of the meaning and implications of the findings as well as to expand the knowledge gained from the prior survey (Study 2). Using mixed methods may increase the power of analytic studies as the complexity of interactions demand more complex research designs to understand them (Sandelowski 2000).

The majority of my thesis is based around quantitative analyses of survey data and as such I can be considered to have taken a 'realist' approach. In this study, I have chosen a qualitative method that lends itself to the realist approach: content analysis. Content analysis counts and measures interview statements, implying that there is a measurable, objective 'truth'. As such, any content analysis needs to be more overtly replicable than other forms of qualitative research as it purports to be as close to an objective analysis as possible. This means that there needs to be a clear 'paper trail', including measures of reliability (e.g. inter-rater reliability) which can be easily understood by independent people. Boyatzis (Boyatzis 1998) proposes that this kind of thematic analysis with reliability

testing provides a 'conceptual bridge' between quantitative and qualitative methodologies.

Content analysis

Content analysis is a form of thematic analysis. It is semi-qualitative in nature in that interview data is transformed into numeric data that can be quantitatively analysed. Content analysis involves assigning numeric codes to segments of texts according to predefined coding rules. Codes can be determined inductively, from the raw data, and deductively, based on prior theory or research. Coding units can be a single word, sentence or paragraph representing a theme (Weber 1990). Codes can be both manifest (explicit in the text) and latent (inferred meaning from the text) (Boyatzis 1998). Codes are used to group together segments of text that contain similar material or themes. These codes can be counted for each individual, resulting in data that can be analysed quantitatively using frequencies and chi-square analyses of group differences. This method should permit inferences to be made by systematically identifying features of the text (Krippendorf 1980).

There are some potential problems and limitations with this method. Some of the advantages of qualitative methods lie in their ability to provide participant-centred information that is rich in context and meaning. Content analysis can lead to the meaning being removed from the context. The frequent occurrence of a word or topic within an interview can simply reflect the interviewee's willingness to talk about the topic and not the importance of the topic to the person or the intensity with which it is experienced (Joffe & Yardley 2004). This problem can be addressed by scoring using a 'presence/absence' method where the presence of a

theme is coded only once rather than an 'intensity' method where instances of a theme are counted within each interview. Using larger coding units to capture meaningful themes can also address this problem. However, larger coding units can mean that multiple codes will apply to the same segment of text. This can affect subsequent analyses by causing spurious correlations to occur. The main advantage of this method is that it produces quantifiable data permitting easy comparison with other survey datasets. Some of the same strictures regarding reliability and validity that are used in quantitative data collection can be applied and so the results can be generalised beyond the sampling frame in the usual manner. For example, inter-rater reliability can be calculated by having two or more researchers coding the same interview data. Arguably this is simply training researchers to code in the same way, but this reliability testing results in consistency of judgement (Boyatzis 1998) and means that codes must be openly explicit and replicable in order to be taught to other people.

I am using this method to allow easier comparison between the interview method and the survey method. The epistemological stances of the two methods are sufficiently close to enable this mixed-method approach yet sufficiently different to allow additional knowledge to be obtained.

Participants

24 patients with a new colorectal cancer diagnosis were recruited to the study through the outpatient oncology clinics at four hospitals in Middlesex and Essex.

Design and Procedure

A purposive sampling approach was used to recruit similar numbers of low and high SES participants. Potential participants were invited to join the study either directly at an outpatient oncology clinic or by being given a questionnaire pack with a consent form to indicate if they were willing to be contacted for an interview either at the clinic or at their home. Nine of the twelve patients (75%) approached directly at the hospital took part in the interview study. 46 colorectal patients returned the survey, of whom 18 (39%) patients indicated that they did not wish to take part in the interview study, 2 (4%) initially indicated willingness to be interviewed, but later declined, and one patient was excluded because of having recurrent disease rather than a new diagnosis.

This left 25 potential participants whose postcodes were linked to census data (Townsend et al 1988) to select those living in high or low SES neighbourhoods to achieve maximum variability in the sampling. 15 (60.0%) patients were selected for interview. The 10 patients not interviewed included 1 whose SES could not be established from the information provided, 7 patients who had closer to 'average' SES and 2 patients who were approached but who were not available when contacted by phone. This resulted in 24 interviewees in total who were divided into two SES groups on the basis of their educational attainment. Participants were categorised as high SES if they had any further educational qualifications (O-level/school certificate and above i.e. age 16+ years, N =12) and low SES if they had no formal qualifications (N = 12). Education was used as the most appropriate maker of SES in this case because of its relationship

to knowledge, literacy, and ability to comprehend and critique information. These are all skills that could be relevant for interactions with medical staff.

Three experienced researchers carried out the interviews which took between 30 and 90 minutes. The interviews were semi-structured using a topic guide (Appendix IX). They began with an invitation for the participant to give an account of their experiences: "Could you start by describing when you first realised that you might have cancer?" This usually resulted in a discussion of the patient's understanding of their illness, their medical treatment (particularly surgery) and the medical care they had received. Additional prompts included: "What has your experience been like with the medical care at this hospital?" and "Could you tell me something about the doctors and nurses that you've come across?" Answers to these questions formed the basis for the main analysis.

All participants agreed to be audio-taped and the interviews were transcribed verbatim except for one case where the tape recorder failed for part of the interview and detailed notes were written instead by one of the researchers (RE). Tapes were numbered and not named to ensure participant confidentiality. The corresponding number/name list is kept in a locked filing cabinet and the tapes will be destroyed on completion of the study.

23 of the 24 (95.8%) interviewees also completed a survey (Appendix X) using items from the CARES-SF medical interactions subscale (Schag & Heinrich 1988). The 31 patients that returned the questionnaire survey, but who were not interviewed, also completed this subscale. Permission was obtained from participants to establish medical details on stage of cancer and types of treatment.

Ethical approval for this study was obtained from the London Multi-centre Research Ethics Committee (see Appendix XI).

Analyses

Transcripts were analysed using content analysis, a form of thematic analysis that assigns numeric codes to segments of texts according to predefined coding rules. Codes for the content analysis were developed by reading through the interviews and loosely organising the topics of the interview into key themes using the Atlas.ti software. Higher-level categories were coded first and then progressively sub-divided into finer grained discriminations (Joffe & Yardley 2004). For example, any statements referring to 'medical care' were coded first. These were then coded into statements that were either positively or negatively valued. These statements were then further divided according to the type of interaction they referred to e.g. personality of doctors, administrative issues, levels of medical expertise. The unit of analysis was defined as an expression which conveyed a complete meaning. This could take the form of a single word, a complete sentence or total statement. Units of text were coded more than once if they conveyed more than one meaning. Codes could be both manifest and latent. A presence versus absence coding method was used; i.e. the presence of a theme is coded only once per interview.

A codebook (Appendix XII) was written and refined by studying five (20.8%) of the transcripts in detail and a coding manual was written. The manual was discussed by two researchers (AS and KR) to clarify the meaning of the coding categories and identify ambiguous areas. 3 transcripts (12.5%) were coded

independently by 2 researchers (AS and KR). Overall inter-rater reliability was calculated using Cohen's Kappa, a measure of percentage agreement. The average kappa percentage agreement across the three transcripts was 76% (range 72% to 82%), indicating a substantial strength of agreement (Landis & Koch 1977). The remaining transcripts were then coded by one researcher (AS).

Data from the content analysis were analysed using chi-square to examine SES group differences in the frequency of satisfaction and dissatisfaction with medical interaction. The survey data were analysed using analysis of variance (ANOVA) to examine SES group differences or trends (recognising the possibility of low power and type II error – see discussion) in satisfaction with medical care as measured by the CARES. The results from the interviews and survey were compared to gauge the value of each method for collecting the desired information.

Results

Respondents

Of the 58 total eligible participants, there were no differences between those interviewed (N = 24) and those not interviewed (N = 34) in terms of age, gender or education. The demographic characteristics of the sample are shown in Table 1. The majority of interviewees were patients from 2 hospitals (hospital A: N = 11, 45.8%, hospital B: N = 9, 37.5%), with another two (8.3%) patients each from two other hospitals. There were 14 men and 11 women aged between 38 and 80 years old (M = 62.59, SD = 11.09). 22 people (91.7%) described their ethnicity as White British with 2 people identifying themselves as White Irish. The majority of

respondents were married (69.6%). 41.7% of the sample were retired with a further three (12.5%) participants reporting that they were too ill to work . As intended, there was variability in SES, with half of the participants without any educational qualifications and half with a household income of £20,000 or less. The average time from diagnosis to interview date was 92 (SD = 65) days.

22 (91.7%) people had had surgery to remove their tumour; the other two received a combination of radiotherapy and chemotherapy in advance of a bowel operation and were waiting for surgery at the time of the interview. In total 7 patients had started chemotherapy and a further 8 were expecting to receive it in the future. Only four participants received radiotherapy, and this was in conjunction with chemotherapy. 11 (45.8%) patients had a colostomy present as a result of the bowel surgery. Six were temporary (reversible) colostomies, 2 were permanent and 3 patients were waiting for a final decision from their medical team regarding the possibility of a reversal. The majority of the patients (N = 15, 62.5%) had either a Duke's A or B stage at diagnosis. The remaining 9 patients all had lymph node involvement and 2 had liver metastases. 13 (54.2%) patients had another co-morbid illness present.

Positive and Negative Evaluations of Care

Participants described the events leading up to their diagnosis and subsequent treatment and commented on their experience with their medical care. Responses were coded as positive or negative comments and people could contribute both. The comments were also coded according to the type of medical care they referred to: 'specialist doctors' (e.g. surgeon, oncologist), 'specialist

Table 1 Demographic characteristics

		N (N = 24)	%
Gender	Male	14	58.3
	Female	11	41.7
Ethnicity	White British	22	91.7
	White Irish	2	8.3
Marital status	Married	16	69.6
	Single	1	4.3
	Divorced	4	17.4
	Widowed	2	8.7
Employment	Retired	10	41.7
	Too ill to work	3	12.5
	Full-time homemaker	1	4.2
	Student	1	4.2
	Employed full-time	5	20.8
	Employed part-time	4	16.7
Education	No formal qualifications	12	50.0
	O level or equivalent (16 years of age)	2	8.3
	A level or equivalent (18 years of age)	1	4.2
	Bachelor degree	3	12.5
	Masters/PhD/PGCE	3	12.5
	Other vocational	3	12.5
Income	Less than £10,000	4	16.7
	£10-20,000	8	33.3
	£20-30,000	5	22.7
	£30,000 and above	5	22.7
	Missing	*2*	*8.3*

nurses' (e.g. stoma nurse, research nurse), 'other doctors' and 'other nurses' (general, non-specific statements about doctors, the medical team, ward doctors or nurses), and 'GPs'.

Participants made slightly more comments about doctors than nurses overall (Table 2). Statements about 'other doctors' were mentioned by the highest number of people (N = 22, 91.7%). Very few people reported entirely negative experiences with care. There were more positive than negative experiences reported in every category, except for GPs. GPs were talked about less during the interviews compared to other types of health professional, but were the only category where more people made negative (N = 6) than positive comments (N = 3). Specialist nursing was the least likely to be criticised, with only 3 people relating negative encounters.

Table 2 Number of people contributing positive and negative evaluations

	Evaluation N (%) N =24			
Medical care	Positive only	Negative only	Both positive and negative	No evaluations
Dr specialist	7 (29.1)	1 (4.2)	10 (41.7)	6 (25.0)
Nurse specialist	13 (54.2)	3 (12.5)	0 (0.0)	8 (33.3)
Dr other	7 (29.1)	3 (12.5)	12 (50.0)	2 (8.3)
Nurse other	7 (29.1)	5 (20.8)	7 (29.1)	5 (20.8)
GP	2 (8.3)	5 (20.8)	1 (4.2)	16 (66.7)

People often related both positive and negative medical interactions, particularly when discussing their doctors (specialist = 41.7%, general 50.0%).

This may be partly because people who made negative comments tried to balance their statement by reporting something that was positive about their experience as well. Reading through the statements, we identified 10/15 patients who made negative comments and then tried to say something that would reduce the impact of the criticism they were making. The following quote illustrates this effect where the respondent says 'I'm not saying ...' to distance himself from being overly critical:

> "*We went in there and we were told 'ask any question you like'. As soon as you started asking questions, he's a bloody academic, he didn't like it. He had, I'm not saying he's not brilliant, I'm not saying that.*" (ID 617)

Nobody made only negative statements across all of the care categories. 5 people had entirely positive experiences and 19 people described both. Overall, this suggested a fairly high level of satisfaction with medical interactions.

Medical Interaction Themes

The content of the evaluative statements was also explored (see Table 3) and five themes were identified:

- Interpersonal Relationships – the quality of the relationship between the patient and the medical team and the perceived personality of the physician (Box 1)
    - Positive: is a caring person, takes time to listen or do extras, provides reassurance, is positive, is attentive or helpful, shares jokes, is hard working.

  - Negative: has an uncaring attitude, is rough or blunt, is rushed, doesn't provide emotional/supportive care or has a poor bedside manner, is paternalistic, is lazy, ignores patients.

- Expertise – the level of expertise possessed by the physician, perceptions of trust and confidence (Box 2)
  - Positive: care provider knows what they are doing and is a professional person. The patient perceives they are getting the best care available, wants to do what they are told by doctors, feels grateful for care.
  - Negative: care provider does not know what they are doing, does not have adequate skills or knowledge, does not look at notes properly, tells you things that are incorrect or gives conflicting information, does something wrong. Patient does not believe what the physician is saying.
- Communication and disclosure – ability to convey meaning about cancer and treatments (Box 3)
  - Positive: tells you everything, talks clearly, explains technical things, answers questions, provides information.
  - Negative: doesn't tell everything, is too technical, doesn't answer questions, gives information at the wrong time, is not explicit, doesn't provide enough information.
- System – experiences of the NHS/care system (Box 4)
  - Positive: seen quickly, NHS better than expected, support services readily available.

  - Negative: delays or long waiting times, notes or scans not available during consultations, lazy or sloppy administration, support services inadequate, didn't see right doctor, not enough staff available.
- General (Box 5)
  - Positive: overall care has been good, general favourable comments
  - Negative: overall care has been bad, general critical comments

Table 3 shows the distribution of the comments amongst these themes. Patients most frequently talked about the personalities of their medical team and the nature of the relationship they had with them. The most positive comments were in this category, suggesting it is an area valued by patients. The positive personality/relationship theme occurred most frequently in the 'specialist doctor' category, with 12 of the 17 people who contributed positive statements making comments in this theme. Many patients specifically reported that their doctor's personality demonstrated that he or she was a caring and trustworthy person. Making a judgement in this area appeared to be one way that patients assessed the quality of the care they were receiving:

> "*He (consultant) was a really nice man. He come out and he examined me and he said 'look, everything went really well for you'. He said 'we've taken away the whole cancer from your body'... And I was very relaxed for a guy that was never in a hospital because the team and Mr X (consultant) was so confident.*" (ID 552)

Patients may find it more difficult to form opinions about either medical expertise or the quality of the information they received as these are novel. They are more

confident about evaluating personal relationships because this is something they do regularly in their everyday lives.

Most negative comments were in the 'system' category showing that there were levels of frustration around the organisation of care. The negative 'system' theme occurred most frequently in the 'nurses other' category. 9 of the 12 people making negative remarks about 'nurses other' made them in this area. These comments were often about the nurses on the hospital wards being under-trained or over-stretched resulting in poor quality care. Again, organisational or administrative ability may be areas that patients are confident about criticising because it is a part of most people's everyday lives, whereas 'expertise' and 'disclosure/communication' themes required the ability to judge novel medical information. For example, people often used non-medical analogies to illustrate the problems they had with the care system:

This quote (ID 559) is from a man who is a store controller and runs a goods department for a large American company. He is talking about waiting for a scan and compares it to running a production line.

"*Well I was due through the machine at three o'clock. At twenty to three they gave me the liquid. So I had to force that down and instead of going through the machine at three o'clock I went through at twenty past three, so once you get a backlog it escalates in this case. No one gave an apology... And if you like, I know the NHS has got its problems, but these sorts of problems, if you like, are localised ones. It's not a case like you're running a production line or something like that. And at the end of the day we are the end users. Ok, I know, you see it on the*

Table 3 – Content of comments about medical care

Medical care		Content of evaluations – Number of people making comments (%)					*Total number of comments*
		Relationship	Expertise	Disclosure	System	General	
Drs specialist	Positive N = 17	12 (70.6)	9 (52.9)	3 (17.6)	3 (17.6)	2 (11.8)	*29*
	Negative N = 11	7 (63.6)	3 (27.3)	4 (36.4)	2 (18.2)	0 (0.0)	*16*
Nurses specialist	Positive N = 13	9 (69.2)	4 (30.8)	6 (46.2)	1 (7.7)	1 (7.7)	*21*
	Negative N = 3	1 (33.3)	0 (0.0)	0 (0.0)	2 (18.2)	0 (0.0)	*3*
Drs other	Positive N = 19	4 (21.1)	4 (21.1)	6 (31.6)	2 (10.5)	10 (52.6)	*26*
	Negative N = 15	3 (20.0)	6 (40.0)	9 (60.0)	7 (46.7)	0 (0.0)	*25*
Nurses other	Positive N = 14	10 (71.4)	2 (14.3)	1 (7.1)	0 (0.0)	4 (28.6)	*17*
	Negative N = 12	4 (33.3)	3 (25.0)	2 (16.7)	9 (75.0)	2 (16.7)	*21*
GP	Positive N = 3	3 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	*3*
	Negative N = 6	0 (0.0)	6 (100.0)	1 (16.7)	1 (16.7)	0 (0.0)	*8*
Total number of comments	Positive N = 66	38	19	16	6	17	
	Negative N = 47	15	18	16	21	2	
	Both N = 113	*53*	*37*	*32*	*27*	*19*	

television, NHS is having problems, but everybody has problems, but at the same time it's up to the people, if you like, who are employee infantry, if you like, basically they can resolve them before it happens."

This next quote is from a policeman (ID 627) who is describing the delay he experienced in receiving his diagnosis which he compares to leaving someone bleeding in a street without helping them.

"*Why did it take from that point to this point to be told about it, why was there this big gap you know?... because its four and half months down the road, these things (liver metastases) might have been just minute... I said 'in fact if I find out any more you'll be up for manslaughter'...which is causing the death of somebody by negligence it is, isn't it? It's like me seeing you in the street, if I just put that pad over your head I'm going to stop some of the blood coming out, to let him bleed you know, ...but it's that annoying fact that you think that maybe somebody had really let you down and why?.*"

These two quotes show how people assess system failures in terms of their own experiences.

Overall the positive comments most frequently referred to relationships with physicians, whereas negative comments were most frequently about system failures. Notably there were also far more positive comments in the 'general' category whereas negative comments were about specific incidences. These bad experiences were important because they could result in adverse health consequences. For example, one patient discussed his delayed diagnosis (four and half months) despite visiting the hospital for appropriate tests. He believed that this delay may have caused his illness to reach an incurable stage. In another

instance, one hospital experienced a disruption in the Macmillan nursing service (one nurse had left, one nurse was on maternity leave and they were unable to provide usual care). The Macmillan nurses were largely responsible for distribution of disease information and providing patient support. When the service was not operating fully, patients said that the lack of information led to increased worry and distress. These cases illustrate the impact that poor care experiences can make to cancer patient's lives.

Comparison of survey items with interview themes

Supplementary quantitative information about communication with medical staff using 6 items from the Medical Interactions subscale of the CARES (Schag et al., 1988) was also collected. 23 of the 24 people taking part in the interviews completed it. Non-interviewees (N = 31) had higher CARES scores (M = 3.21, SD = 4.44) than interviewees (M = 1.43, SD = 1.70), this was not statistically significant (F [1,54] = 3.00 p = 0.09), but the p-value suggests the presence of a trend towards non-interviewees being more dissatisfied with their care.

The survey data were compared with the interview data in a number of ways. Firstly, the content of the survey items was compared with the content of the negative interview comments. Secondly, negative interview scores were calculated and compared with CARES scores on a case by case basis to see how well they corresponded.

Four of the six items from the CARES fall within the communication/ disclosure theme identified in the interviews (withholds information, don't explain what they are doing, difficulty asking questions, difficulty understanding). 11 of the 12 people indicating dissatisfaction on the CARES marked one or more of these

items. 16 people made negative comments about communication/ disclosure during the interviews. The item about expressing feelings to care providers seemed to be more closely related to the personality/relationship theme. The final item concerned control ('I would like to have more control over what the doctors do to me') and this theme did not appear in the interviews at all, despite being the items with the highest frequency of people indicating any dissatisfaction (N = 8).

Table 4 – CARES items

	Response options N (%)				
CARES items N = 23	Not at all	A little	A fair amount	Much	Very Much
Medical team withholds information	18 (78.3)	5 (21.7)	0 (0.0)	0 (0.0)	0 (0.0)
Doctors don't explain what they are doing	18 (78.3)	4 (17.4)	1 (4.3)	0 (0.0)	0 (0.0)
Difficulty asking doctors questions	19 (82.6)	4 (17.4)	0 (0.0)	0 (0.0)	0 (0.0)
Difficulty expressing my feelings to doctors/nurses	19 (82.6)	3 (13.0)	1 (4.3)	0 (0.0)	0 (0.0)
Difficulty understanding doctors	20 (87.0)	3 (13.0)	0 (0.0)	0 (0.0)	0 (0.0)
Like to have more control over doctors	15 (65.2)	6 (26.1)	2 (8.7)	0 (0.0)	0 (0.0)

Table 4 shows the distribution of the responses to the CARES items. Only 12 people indicated any dissatisfaction across any of the items, and these were at the lower ends of the scale. In contrast, 15 people made negative comments in the interviews, suggesting that interviews might pick up a greater number of instances of dissatisfaction because it allowed people to relate specific incidents.

A 'negative score' for the interviews was calculated by adding together the presence of negative comments across the five medical care categories (specialist doctor, specialist nurse, other doctor, other nurse and GP). This resulted in a

score from 1 to 5 with a higher score indicating negative comments in more areas i.e. more negative experiences. There was a non-significant positive correlation indicating some correspondence between reporting negative experiences during the interview and CARES scores ($r = 0.24$, NS). There appeared to be two cases (both high SES and male) who did not report negative experiences in the interview but had relatively high CARES scores and four cases (one high and three low SES, all male) who made a number of negative comments in the interviews but had low CARES scores.

Demographic Differences in Perceptions of Care

Patients with disease stages Dukes A or B were compared with those with more advanced disease (Dukes C1 and above) in terms of their medical interactions. There were no differences between the two groups in any aspects of the interview data or in ratings on the CARES subscale. Responses from patients at different hospitals could be examined comparing patients from two hospitals where there were sufficient numbers to perform these analyses. These analyses showed no difference between these two hospitals in responses in any category. There were also no differences between men and women in any of the ratings. Age was unrelated to the 5 medical interaction themes overall or the CARES subscale, but younger patients reported more negative care experiences with specialist doctors ($r = 0.58$, $p<0.01$, $N = 20$) and specialist nurses ($r = 0.69$, $p<0.001$, $N = 20$).

Socio-economic Differences in Perceptions of Care

Chi-square analyses, using Fisher's exact test where appropriate, examined SES differences in medical interactions. Fisher's exact test can be used for 2 x 2 chi square tables where the expected cell frequencies fall below five. It calculates the exact probability rather than a critical value.

There were equal numbers of men and women in the low SES group (i.e. 6 men and 6 women) and slightly more men in the high SES group (8 men and 4 women) but this was not significantly different. The mean age in the low SES group was 64.58 (SD = 10.1) years and 60.1 (SD = 11.4) in the high SES group, but this was not a significant difference. Of the nine people who had lymph node involvement, 6 were in the low SES group and 3 in the high SES group, but this difference was not statistically significant.

There were significant differences between the education groups when talking about 'specialist doctors' in both positive (χ^2 (1) = 5.04 $p<0.05$) and negative (χ^2 (1) = 4.20 $p<0.04$) categories. Table 5 shows the distribution of positive and negative comments by education within each of the care provider categories. Patients with less education were less likely to contribute any positive or negative comments in the care provider category 'specialist doctor'. Half of the less educated participants made no comments in this care category compared with all 12 of the more educated participants. This may indicate a reluctance of less educated participants to make evaluations about the specialist care they are receiving. There were no significant differences between the two groups in any of the other care provider categories. There were also no educational differences in

terms of the distribution of the five evaluation themes: personality/relationship, expertise, communication/disclosure, system or general.

Table 5 Positive and negative evaluations of medical care by level of education

Medical care		Further Education N (%) No (N = 12)	Yes (N = 12)
Drs specialist	Positive	6 (50.0)	11 (91.7)
	Negative	3 (25.0)	8 (66.7)
Nurses specialist	Positive	6 (50.0)	6 (50.0)
	Negative	1 (8.3)	2 (16.7)
Drs other	Positive	9 (75.0)	10 (83.3)
	Negative	10 (83.7)	5 (33.3)
Nurses other	Positive	9 (75.0)	5 (41.7)
	Negative	5 (41.7)	7 (58.3)
GPs	Positive	1 (8.3)	2 (16.7)
	Negative	4 (33.3)	3 (25.0)

There was a difference between the two educational groups in the CARES scores, but the low education group had slightly *higher* satisfaction ($F(1,22) = 4.76$ $p = 0.04$), although this was a relatively small effect (effect size = 0.4) indicating a high level of overlap between the two groups. However, of the four people with high negative interview scores and low CARES scores, 3 were low SES, possibly indicating that low SES participants were better able to communicate their dissatisfaction via a face-to-face discussion.

Discussion

Patients in this study predominantly expressed high levels of satisfaction with their care, particularly care from specialist nurses. Some people also expressed extreme dissatisfaction, but often in one specific area, with positive experiences in other fields. The tone of interviews suggested that patients are reluctant to be critical of their medical care, particularly care from specialist professionals, perhaps because they feel less able to judge expertise in this area. Only GPs received more negative than positive comments overall, although the total numbers of comments about GPs were lower than in other categories. In contrast to the comments about specialist care, the majority of the criticisms about GPs concerned their expertise. Patients may feel that GPs display a lack of knowledge about cancer, or at least less than they expect. Specialist nurses received the most 'positive only' ratings with no criticisms at all. These comments often referred to aspects of their interpersonal skills and their ability to disclose and communicate information about cancer. This suggests that specialist nurses are extremely skilled in managing all aspects of patient communications.

The themes identified from the qualitative interviews (i.e. relationship, expertise, disclosure, system and general) were similar to those from other studies (Freedman 2003, Wright et al 2004). The most frequently commented themes (both positive and negative) were in the area of personal relationships or interpersonal skills, and this also had the highest numbers of positive comments. There was some support for the idea that people judge the quality of their care based on their physicians' personality, highlighting the importance of presenting a 'caring personality' in terms of patient satisfaction. The most negative comments concerned aspects of the 'system' and organisation of services including waiting

times for tests, administration of appointments and training and supply of nurses. Perhaps patients feel comfortable criticising this area because organisational skills are a part of most people's lives. Patient satisfaction cannot be achieved only by improving the communication skills of medical care professionals because poor service organisation can eclipse improvements in these areas (Shilling et al 2003).

This research also offered new insights. Other qualitative studies have not coded the direction (i.e. positive *vs.* negative) of people's experiences. The present study identified areas of good and bad practice as well as illustrating areas that patients value. The majority of patients reported both positive and negative experiences, sometimes in the same area of care. For some people this probably reflects a desire to balance criticism with positive statements but for most it appeared to represent their mixed experience of care.

The quantitative (CARES questionnaire) data revealed one area that was not discussed in the interviews. Over a third of the patients indicated that they would like more control over what the doctors did to them. The content analysis failed to pick up this issue perhaps because the coding was at a more 'explicit' level and issues surrounding control are more abstract and only inferred implicitly from the interview statements. It could be argued that control issues underlie many problems of dissatisfaction. For example, this person complains about the timing of visits from the district nurse:

"We were very sort of confined. You know, they're short staffed and they don't tell you when they're coming. They say morning probably and then it might get into the afternoon, you see, so you're sort of stuck all day." (ID 397).

They do not refer specifically to lack of control, but this shows how control of their day was taken away. Being ill does take away some control and ability to plan

because of the physical limitations imposed and the necessity of having to rely on care providers. It is possible that asking most people in this situation if they would like more control will result in an affirmative answer. This demonstrates that interview and survey methods may draw out different aspects of satisfaction. However, comparing the interview and survey data showed that some people showed more dissatisfaction on the survey and some in the interviews, with no clear pattern of differences. Interviews can elicit more specific examples of poor care whereas surveys can uncover more general concerns.

There was little evidence of differences in care experiences depending on the patient's SES. Study 2 found that lower SES patients reported slightly more dissatisfaction with medical services on the CARES medical interactions subscale and that had provided the impetus for the present study. However the quantitative difference was not confirmed in this new sample and the qualitative data were in the opposite direction. Less educated patients provided fewer evaluative statements overall in the interviews and tended to list events without expressing whether the care was good or bad. The only significant difference was that lower SES patients were less critical of medical care from specialist doctors. This could be because of reluctance to criticise the care they receive, but the other categories showed no differences and the effect was weak, suggesting that it might be a chance finding. Another difference between Study 2 and this study was the length of time from diagnosis to assessment of patient satisfaction. Study 2 included patients up to one year after diagnosis (M = 257, SD = 112 days post-diagnosis) whereas this study interviewed patients generally within the first three months after diagnosis (M = 92, SD = 65 days post-diagnosis). This disparity may have

affected the results in that differences in satisfaction with care by SES may only arise over time. Longitudinal data is needed to test this hypothesis.

Previous research has found differences in the way that physicians communicate with lower SES participants by providing less information and using a more directive consulting style (Macleod et al 2004, Willems et al 2005). I aimed to explore patients' reporting of their medical experiences and so doctors were not observed. Differences may exist in consulting styles between patients, but if so, it is not having striking implications for patient dissatisfaction.

This study could have failed to detect SES differences because it was underpowered. The results from Study 2 could have disguised a much larger effect that would be revealed during the interview process. Post-hoc power analysis, using g-power software, showed that the power of the study to detect a large effect size was 0.69. Good power in a study is usually rated at 0.80. Two additional participants were required to reach a power of 0.80. However, there should be enough power to show any trends in the data, even if they do not reach statistical significance. No trends were seen and the addition of two extra participants is unlikely to have changed the results in a dramatic manner. Another reason for failing to detect SES differences could be because of a mis-match between the educational levels of the interviewers (all of whom had a number of years of further education) and the SES of the interviewees. This could result in difficulties with establishing rapport. However, interviewers successfully elicited more negative comments from the less educated interviewees than the survey method suggesting that this was not a real limitation. The interviewees were also self-selecting to a certain extent and the people who were not interviewed had

higher levels of dissatisfaction on the CARES items. Low SES patients with higher dissatisfaction may have chosen not to be contacted for an interview.

There were a number of strengths to this study. It provided a mixed-gender sample with slightly more male (58%) than female (42%) participants. Previous qualitative studies have been restricted to women's experiences with breast cancer. Recruiting men to qualitative interviews is often more difficult. This study found no gender differences in experiences with care. In terms of other demographic factors, younger age was associated with increased criticism of specialist care from both doctors and nurses, which has also been reported in another study that had a high proportion of lower SES participants (62% left school < 16 years) (Davidson & Mills 2005). Other studies have been dominated by high SES participants and may not provide a balanced view (e.g. Freedman 2003)).

This study showed that although there are SES differences in satisfaction with medical interactions, these are likely to be small. There are still some unanswered questions concerning the impact of different hospital centres on these differences and a further multi-centre study could enhance the understanding of this topic. In addition, longitudinal data could show if differences in satisfaction with medical interactions emerge over time, and whether this could affect psychological adjustment in the longer-term. The qualitative data collection provided a fuller picture of the care experience of colorectal cancer patients and emphasised the importance of physician's interpersonal skills and difficulties with the administrative system that were affecting patient satisfaction.

Box 1 – Interpersonal Relationship

Positive

"The girls (nurses) at the Unit are so helpful and everything like that, I mean they're so nice, you can't ask for a better team." (ID 586)

"Mr X, even though he's now registrar to someone else, he came by my bed several times to ask how I was getting on. And Miss X, the new registrar, she's been very kind and very gentle, you know. Everybody's been very considerate to me." (ID 574)

"Professor X was brilliant, he's such a, he's just, I can see in his eyes. I mean they are all there for that type of job but sometimes it can be a career thing and sometimes it can be loyalty to people and that man is definitely loyalty to people. "(ID 311)

Negative:

"He was bit sharp, um, don't know his name but, I mean at the end I did say to him um, I said when you do meet patients can you just at least smile a bit because you make, you made me very uneased." (ID 311)

"He (surgeon) tended to talk down to them a bit, he tried to be paternalistic to me and I blew him right out of the water." (ID 371)

"The registrar [was] very poor, very poor manner, very poor his way of dealing with the whole situation... it was just the way he came across, I mean he walked in the room he said... 'hello Mrs Smith' he said 'well you know you've got cancer' just like that, it just came out and I thought, and it was just the way he said it ... it was just awful I thought, I hadn't even sat down in the chair before he'd sort of said it you know and I don't think he was very experienced at the way you go about these things." (ID 368)

Box 2 – Expertise

Positive:

"Everything on the specialist side is fine, it's good, it's acknowledgeable, they know what they're talking about, they gave suitable, appropriate advice." (ID 1095)

"I've got faith and strength in the surgeon because I was very impressed by what he said to me and erm very professional. And so that gave me a lot of confidence. And I think that was one of the best things to do is to actually talk to your surgeon and you think yep that's ok and well I've got the best person on the job that I can possibly get." (ID 384)

Negative:

"The health care assistants, the only thing I can say about them is that they're totally incompetent... They don't know the significance of any of the things they are doing, don't know the significance of a moderately high temperature." (ID 1095)

"My GP doesn't know anything much about, he knows a very limited amount about bowel cancer, he knows what it is and what they do for it, but he didn't understand how you are afterwards, that's physically more than mentally." (ID 368)

Box 3 – Communication/Disclosure

Positive:

"The nurses were actually very good, they sort of told me everything they were going to do and explained everything and told me what I should be doing if, you know, which I tried to follow." (ID 950)

"All of the doctors that I've come across have tried not to use long words and I think, if you like, this, if you like, is a good thing." (ID 559)

"I am one of these people that have to know everything. Everything I asked they gave me the answers to. I found the treatment very good, before I came into hospital, during hospital, the doctors were very good, and anything I asked." (ID 352)

Negative:

"I was just prepared to listen to everything that was said and I still don't think I heard the word cancer... I asked my husband again after that 'what was said?' and I needed him to say the word, but nobody would use the word." (ID 343)

"When they're using technical terms and things you know you get a bit confused sometimes." (ID 1112)

Box 4 – System

Positive:

"There's all these people saying the NHS is no good and I say well from what I've seen it's excellent." (ID 384)

"Once they discovered it (cancer), they acted so quickly at [hospital name], and I know people complain about [hospital name], but they complain about all hospitals, but as far as I'm concerned, it couldn't have been better." (ID 368)

Negative:

"He didn't have the scan with him. Now that was the bit that pushed me. I'm not saying his notes weren't right, I'm not saying any of that, but when you had a scan six months ago that nobody's bothered to look at, you've had another one in hospital, you really want it there don't you?" (ID 627)

"I feel I'm delicate inside still which is only natural like, but there was no 24 hour contact number and there was no backup for relatives of anything" (ID 552)

Box 5 – General

Positive:

"The medical care at the hospital was absolutely marvellous." (ID 560)

"They seemed all right to me, no fault to find in them at all. Er the doctor was very good, the nurses done their best." (ID 587)

"All the doctors and nurses that I've come across have been great." (ID 372)

Negative:

"I had a couple of nasty experiences, but that was just bad luck basically." (ID 559)

"There again, I haven't had that much contact with that many nurses. I'm not so keen on nurses really." (ID 372).

CHAPTER 8

Study 4: Socioeconomic status differences in psychosocial wellbeing of cancer patients

Introduction

The results from Study 2 suggested that SES might moderate the extent of anxiety associated with a stressful situation. Higher SES cancer patients reported relatively lower levels of anxiety across all disease stages, whereas lower SES patients had increasingly higher anxiety with more advanced disease stage. These results were from a comparatively small sample of colorectal cancer patients and clearly they need to be replicated. A larger sample comprising more diverse disease sites and assessing other potentially stressful characteristics of the medical situation in addition to disease stage, would be useful for confirming these findings.

Potential cancer-related stressors were described in Chapter 2, including characteristics of different treatments and co-morbid illness that could affect psychosocial wellbeing. Treatments such as chemotherapy, radiotherapy or surgery commonly cause symptoms of illness including fatigue, pain and sickness. These symptoms experienced at chronic levels are debilitating and connected to psychological distress. Cancers tend to be diagnosed at later ages and consequently many people will already be diagnosed with co-morbid conditions prior to their cancer diagnosis. Patients with co-morbid illness may also be likely to report increased depressive symptoms.

The present study examines the relationships between disease stage and SES taking account of treatment and co-morbid illness on psychosocial wellbeing in a sample of cancer patients. The sample used in this study differed in a number of ways from that used in Study 2: it comprised a mixed sample of breast, prostate and colorectal cancer patients, it was larger (N = 352), patients came from multiple hospital sites and all patients were assessed within a specific time-frame post-diagnosis (up to three months). The larger sample is beneficial in terms of additional power to detect SES differences. The mixed-cancer population from multiple hospital sites enables a broader, more wide-ranging overview of cancer patient experiences so that any effects will be more generalisable. Additionally, as all of the patients were observed within a similar time frame since diagnosis they should be more likely to be experiencing the same kind of psychological challenges than those in Study 2 where there was a difference of up to a year in the timing. The assessment of SES in this sample was also more comprehensive and included markers of income, education, material assets, subjective SES and an area-level indicator. Comparing the outcomes using the different markers could help identify the most appropriate measure for this type of population and the ability of the different SES markers to detect differences in psychosocial wellbeing could reveal information about the mechanisms of any SES effects.

As in Study 2, I will test the hypothesis that SES interacts with characteristics of the stressful situation to result in adverse psychosocial outcomes for those from more deprived backgrounds.

Hypotheses

1. Lower SES patients will have poorer psychosocial wellbeing than higher SES patients.
2. Cancer-related stressors will affect psychosocial wellbeing. Patients receiving chemotherapy, or being diagnosed with invasive disease will have worse psychosocial wellbeing.
3. Patients with a co-morbid illness will experience poorer psychosocial well-being.
4. There will be an interaction between SES and cancer-related stressors (disease stage, treatment, co-morbidity) on psychosocial wellbeing.

Method

Participants

This was a longitudinal survey of patients who had received a diagnosis of breast, prostate or colorectal cancer. Patients were recruited from nine hospital sites in and around North London, Middlesex and Essex. There was a two year recruitment period (February 2003-January 2005). 352 patients were recruited during this period. Potential participants were identified by oncology and research nurses in each hospital. Patients presenting with severely advanced disease were excluded from the study due to its longitudinal nature. The research or oncology nurses who recruited participants were responsible for making an assessment of the suitability of each patient for inclusion in the study. Not all of the hospitals maintained records of which patients were approached compared to those that consented to participate. Detailed information from one health trust (two hospital

sites) revealed that 187 patients were approached by a research nurse to participate in the study, of who 125 agreed to participate, representing a response rate of 67%.

Design and Procedure

New breast, prostate and colorectal cancer patients seen at participating hospitals during the trial period were invited to join the study by research or oncology nurses at outpatient oncology clinics. They were given a questionnaire pack with an information sheet and consent form which included the contact details of a researcher. Potential participants were invited to contact the researcher with any questions regarding the study. Questionnaire packs were returned via freepost mail to UCL. Participants were invited to provide address information so that the longitudinal aspect of the survey could be completed from UCL. Address information was kept separately from the questionnaires. Questionnaires were numbered and not named to maintain anonymity. Hospital staff were given feedback regarding which participants (by number) had returned completed questionnaires and non-responders were sent a second survey after a one month period had elapsed. Formal consent was also sought from each patient for access to their medical records. Ethical approval was obtained from the London Multi-centre Research Ethics Committee (see Appendix XI).

Participants completed a self-report questionnaire covering a range of psychosocial wellbeing outcomes and resources: quality of life, social problems, experience of medical care, social support, anxiety, depression, benefit finding, disclosure, mastery, optimism and coping strategies. Demographic information

included ethnicity, gender, and socio-economic status (SES) (see Appendix X). Surveys were completed at two time points: first at 1-3 months post-diagnosis and then again 9-12 months post diagnosis. Data for this chapter were taken from the first survey.

Measures

Markers of Socio-economic status

Socio-economic status (SES) was indexed using the same individual-level indicator described in Studies 1 and 2. Three items reflecting material circumstances and education were assessed: car-ownership or not (score 0/1), home-ownership or not, and some higher education versus none. This resulted in a composite score from 0 to 3, with '3' representing high SES (as opposed to high deprivation i.e. reverse scored compared to its use in Studies 1 and 2). Again the two most deprived categories were combined resulting in a three category marker of socio-economic status: high (score 3) (car-owner, home-owner and higher education), medium (score 2), and low (score 0-1).

The Townsend Index (Townsend et al 1988) is an area-level indicator of deprivation based on levels of car ownership, housing tenure, unemployment, and overcrowded living conditions as recorded in the census across enumeration districts (on average about 200 households). This Index was also used in Study 1. A score of zero represents the national average with negative values representing less deprivation (higher SES) and positive values representing more deprivation. Postcode information was collected for each individual giving address information and was linked to enumeration districts; the Townsend score for the district was

assigned to the individual. The Townsend index score was based on the data from the 1991 census.

Income was assessed with a single item question: "Think about your family's income, which category would describe the total annual household income? (including your own and partner's salary and any benefits)". There were 8 response categories ranging from less than £10,000 per year to more than £70,000 per year.

Subjective SES was assessed using a pictorial, 10-rung ladder (Adler et al 2000). Participants were shown the ladder together with the following instructions: "Think of this ladder as representing where people stand in the UK. At the top of the ladder are the people who are the best off, those with the most money, most education and most respected jobs. Those at the bottom are the people who are worst off with the least money, least education and least respected jobs or no job. The higher up you are on the ladder, the closer you are to the people at the top, the lower you are the closer you are to the people at the bottom. Please place a large 'X' on the rung where you think you stand at this time in your life relative to other people in the UK." This results in a ten category measure of subjective SES with '1' representing low SES and '10' representing high SES. The subjective SES measure was only assessed at the second round of data collection and consequently was only available for 235/352 (67%) of participants.

Medical characteristics

Information on medical characteristics was obtained by accessing individual's medical records. Information from medical records were obtained for 282/352 (80.1%) of participants. Requests were made to access the medical

records for the remaining patients, but participating hospitals failed to provide the required information mainly due to lack of staff time and resources.

Information regarding disease stage, treatment and presence of co-morbid illnesses were collected. Patients were classified into two disease stage groups: invasive and non-invasive. Those with 'invasive' disease were patients who had lymph node involvement or distant metastases. There were four main treatment types: surgery, radiotherapy, chemotherapy, and hormone therapy. For cases where information from medical records were lacking, self-report items on the survey regarding disease stage ("Has your cancer spread to any other part of your body?") and treatment ("Have you already received any of the following treatments?") were used. The questionnaire did not contain an item about co-morbidity and so this information was only available for the patients whose medical records were accessed.

Psychosocial wellbeing

Psychosocial wellbeing was assessed with a number of scales previously used Study 2: quality of life, social difficulties, anxiety, depression and medical interactions. Additionally, one measure of positive psychological wellbeing assessing 'benefit finding' was included.

Quality of Life

Quality of life was assessed using the Functional Assessment of Cancer Therapy (FACT-G) (Cella et al 1993) with the appropriate cancer specific subscales for breast, prostate or colorectal cancer. There are five subscales: physical (7 items, e.g. 'I have pain'), functional (7 items, e.g. ' I am able to enjoy the things I usually do for fun'), social/family (7 items, e.g. 'I get emotional support

from my family), emotional well-being (6 items e.g. 'I feel nervous') and a cancer-specific subscale. Participants indicate how true each statement is for them during the past seven days. There are five response options from 'not at all' to 'very much'. The scale range is 0 to 24 for the 6-item scale and 0 to 28 for the 7-item scales, with higher scores indicating better quality of life. A total score is computed from the sum of the physical, functional, social/family and emotional subscales, with a range from 0 to 108.

Social Difficulties

The Social Difficulties Inventory (SDI) (Wright et al 2005) is a 21-item questionnaire designed for use in oncology care. It covers problems in managing personal care, domestic chores and responsibilities, finances and benefits, employment, relationships, sexuality and body image, mobility and leisure activities. Participants rate whether they have experienced any difficulties over the past month. There are four response options with a range from 'no difficulty' to 'very much'. Participants mark the 'no difficulty' box if the question does not apply to them. The scale range is 0 to 63 with higher scores indicating more social problems.

Anxiety

Anxiety was assessed using the anxiety subscale from the Hospital Anxiety and Depression Scale (HADS) anxiety scale (HADS-A, 7 items) (Zigmond & Snaith 1983). Participants rate how they have usually felt over the past week. For example 'worrying thoughts go through my mind' with the response options 'a great deal of the time, 'a lot of the time', 'from time to time but not too often' and 'only occasionally'. Each item has four response options that vary slightly

according to the statement. Positively worded statements (e.g. 'I can sit at ease and feel relaxed) are reversed scored. Items are scored 0 to 3 and summed to form a scale ranging from 0 to 21, with higher scores indicating more anxiety.

Depression

Depression was measured with the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff LS 1977). This scale asks about feelings over the past week and the number of days that they felt that way. For example: "I was bothered by things that don't usually bother me" with response options from 'rarely, none of the time (less than one day)', to 'most or all of the time (5-7 days)'. The shorter 10-item version (Kohout et al 1993) was used, but retained the original response options. The CES-D is scored 0-3. Items are summed to form a scale that ranges from 0 to 30 with higher scores indicating more depression.

Benefit Finding

This is a measure of the perceived benefits that may arise from the experience of having cancer. This scale was originally developed for use with breast cancer patients (Antoni et al 2001). It is a 17-item unidimensional scale. In this study the item set was reduced from 17 to 11 and excluded items that referred to social support and the role of other people because of their overlap with items on the perceived social support scale that was also used in this survey. The remaining items assess benefits such as acceptance of life's imperfections and developing a sense of purpose in life. In this sample, the reduced scale had good internal reliability (α=0.95). The stem for each item is "Having had cancer has....", followed by a possible benefit of having had cancer, for example "contributed to my overall emotional and spiritual growth". There are five responses options: 'not

at all', 'a little', 'moderately', 'quite a bit' and 'extremely', scored 1-5. Items are summed to form a scale scored 11 to 55.

Medical Interactions

Communication with medical staff was assessed using the 4-item subscale from the Cancer Evaluation and Rehabilitation System – Short Form (CARES-SF) (Schag & Heinrich 1988). The items refer to levels of information provided, understanding the information provided, levels of control over treatment, and difficulty asking questions. Participants are asked how much each statement applies to them during the past month. For example: 'I find that the medical team withholds information from me about the cancer'. There are five response options from 'not at all' to 'very much'. Items are summed and divided by the number of items answered, resulting in a scale from 0 to 4. Higher scores indicate poorer communication with medical staff.

Analyses

Data were analyzed using analysis of variance with SES group and medical characteristics as the independent variables, and age, gender and cancer sites as control variables. Psychosocial wellbeing: quality of life, social difficulties, anxiety, depression, benefit finding, and medical interactions, were the dependent variables. The analyses were carried out using four different SES markers (individual SES [car/home/education], Townsend score, income and subjective SES).

The psychosocial variables had small amounts of missing data. In cases where the missing data were related to SES or the proportion of missing data was

greater than 5% (the depression and social difficulties variables only), the analyses were re-run using imputed values based on the subject mean for each scale if at least half of the items had been completed, and any changes in the outcomes were noted.

The effect of clustering due to the different hospital sites was considered and intracluster correlation coefficients were calculated for all of the dependent variables. Most of the dependent variables had small intracluster correlations (range: 0.02-0.04), only the social difficulties variable indicated a medium effect (0.1) (Hox 2002). Any analyses involving this variable included adjustment for clustering due to hospital site.

Lower SES, more advanced disease, receiving chemotherapy and the presence of a co-morbid illness were hypothesized to be associated with poorer outcomes. Having more advanced disease, receiving chemotherapy or having a co-morbid illness were hypothesized to be particularly stressful for lower SES participants, and an interaction between these medical characteristics and SES was predicted.

Results

There were 352 participants. Nine hospital sites took part in recruitment to the study. Recruitment levels varied widely between each hospital site. For example, two hospitals recruited 100 patients each, accounting for 56.8% (200/352) of the full sample, whereas one hospital only recruited 2 participants. Table 1 shows the demographic and medical characteristics of the sample. There were more women (67.6%) than men (32.4%) largely because of the high

proportion of breast cancer patients (204/352, 58.0%) recruited to the study. Ages ranged from 29 to 89 years of age, but just over half of the patients (51.8%) were over 65 years of age. The sample is also predominantly white (84.9%) and married (68.8%). A third of the patients had lymph node involvement or distant metastases (33.5%). The majority had received surgery (81.5%), half had been given radiotherapy (47.2%) and a third received chemotherapy (33.8%). 60% (160/268) of the breast and prostate patients were continuing with some form of hormone therapy. Just under half of the patients had at least one co-morbid condition (45.5%), but information on the presence of co-morbidity was only available for N = 275/352 (78%). The average time since receiving a cancer diagnosis until recruitment to the study was 66 days (SD = 45 days).

Table 2 shows the socio-economic characteristics of the sample. 57.4% had some educational qualifications. 79.5% of the sample were car owners and 80.1% were home owners. These figures were slightly higher than the national ownership figures, particularly for home-ownership (car: 77%, home: 69% (Rickards et al 2004)), but levels of home-ownership vary across age groups and the figures in this sample more closely reflect levels of ownership amongst older adults (home owners: age 60-64 years = 81%, age 65-69 = 73% (Rickards et al 2004). The Townsend score showed that just under half lived in above average deprivation areas (scoring '0' and above). This was also a low earning sample with 52.3% reporting a household income of £20K and under. This could reflect the fact that this was also a largely retired population.

Table 1 – Demographic and medical characteristics of sample

			N (N = 352)	%
Gender	Male		114	32.4
	Female		238	67.6
Age (range 29-89)	65 years and over		145	41.2
	Under 65 years		135	38.4
	Missing		72	20.4
Ethnicity	White		299	84.9
	Black		15	4.3
	Indian/Pakistani		20	5.7
	Chinese		1	0.3
	Other		13	3.7
	Missing		4	1.1
Employment status	Full & part-time		116	33.0
	Homemaker		26	7.4
	Unemployed		13	3.7
	Student		3	0.9
	Disabled/too ill		12	3.4
	Retired		176	50.0
	Missing		6	1.7
Marital status	Married/living with partner		242	68.8
	Widowed		51	14.5
	Divorce/separated		27	7.7
	Single		32	9.1
Cancer site	Breast		204	58.0
	Colorectal		84	23.9
	Prostate		64	18.2
Disease stage	Invasive		118	33.5
	Non-invasive		209	59.4
	Missing		25	7.1
Treatments received	Surgery	Yes	287	81.6
		No	55	15.6
		Missing	10	2.8
	Chemotherapy	Yes	119	33.8
		No	226	64.2
		Missing	7	2.0
	Radiotherapy	Yes	166	47.1
		No	179	50.9
		Missing	7	2.0
	Hormone therapy	Yes	160	45.5
		No	185	52.5
		Missing	7	2.0
Co-morbid illness		Yes	160	45.5
		No	115	32.7
		Missing	77	21.9

Table 2 Socio-economic characteristics of the sample

		N (N = 352)	%
Educational qualifications	Some	193	54.8
	None	143	40.6
	Missing	16	4.5
Car owner	Yes	280	79.5
	No	70	19.9
	Missing	2	0.6
Home owner	Yes	282	80.1
	No	68	19.3
	Missing	2	0.6
Townsend score	Deprived (>0)	156	44.3
	Affluent (<0)	187	53.1
	Missing	9	2.6
Income	<10K	72	20.5
	10-20K	112	31.8
	20-30K	57	16.2
	30-40K	31	8.8
	40-50K	16	4.5
	50-60K	13	3.7
	60-70K	3	0.9
	>70K	7	2.0
	Missing	41	11.6
Subjective SES	1 low SES	6	1.7
	2	9	2.6
	3	21	6.0
	4	28	8.0
	5	57	16.2
	6	58	16.5
	7	35	9.9
	8	10	2.8
	9	9	2.6
	10 high SES	2	0.6
	Missing	117	33.2

The main SES analyses used a composite marker based on educational qualifications, car and home ownership, as previously described in Chapter 3. This resulted in three SES groups: low (N = 62), medium (N = 133) and high (N = 141). There were no differences in the SES distribution of the sample according to hospital site (χ^2 = 2.17, *df* = 1, NS). There were no gender differences between the SES groups (χ^2 = 0.14, *df* = 1, NS). Lower SES was associated with older age (*F* [1,269] = 6.03, $p<0.001$). There were no differences by disease site (χ^2 = 0.07, *df* = 1, NS), but more 'high' (55.4%) and 'medium' (52.7%) SES than low SES (29.5%) participants had received radiotherapy (χ^2 = 9.10, *df* = 1, $p<0.01$). There were no differences between SES groups in terms of the other treatments (surgery, chemotherapy, hormone therapy) or disease stage at diagnosis. However, 76.7% of low SES participants had a co-morbid illness compared to 47.3% of high SES participants (χ^2 = 11.49, *df* = 1, $p<0.001$).

Disease stage, treatment and psychosocial wellbeing

Patients with invasive disease reported worse overall quality-of-life (*F* [1,318] = 4.48, $p<0.05$) (Table 3). These patients particularly had worse emotional quality-of-life (*F* [1,324] = 8.64, $p<0.01$) and a trend for poorer functional quality-of-life (*F* [1,322] = 3.51, $p = 0.062$). Advanced disease status was also associated with increased anxiety (*F* [1,320] = 4.66, $p<0.05$), with a similar trend being seen for depression (*F* [1,300] = 3.43, $p = 0.065$). When the analyses were re-run using imputed data in the depression variable, this association became significant (*F* [1,325] = 5.14, $p = 0.022$, partial eta squared = 0.017) such that those with more

advanced disease had higher levels of depression (Mean = 7.66, 95% CI = 8.37-8.95) than those with non-invasive disease (Mean = 6.02, 95% CI = 5.04-7.00). Social difficulties were higher in those with metastases (F [7, 288] = 12.75, $p<0.01$) but there were no differences between the two groups for benefit finding (F [1,316] = 0.005, NS) or medical interactions (F [1,320] = 2.09, NS). The effect sizes were all small.

Receiving a particular treatment or not (e.g. surgery or not, chemotherapy or not) and their associations with psychosocial wellbeing were explored using univariate ANOVAs controlling for age, gender and disease site. There were no differences in any of the psychosocial wellbeing variables depending on having radiotherapy or hormone therapy (NB using just breast and prostate patients for the analyses with hormone therapy). Receiving surgery (M = 8.16, SE = 0.64) was associated with slightly decreased social difficulties compared to those who did not receive surgery (M = 9.46, SE = 0.32) (F [7,300] = 6.19, $p<0.05$), although this association becomes non-significant when using a variable that includes imputed values for missing data. Those who had received chemotherapy reported worse functional quality-of-life (M = 15.21, SE = 1.57) (F [1,339] = 4.14, $p<0.05$) and more dissatisfaction with their medical interactions (M = 0.32, SE = 0.06) (F [1,336] = 13.57, $p<0.001$) than those who did not (functional: M = 18.86, SE = 0.57, medical interactions: M = 0.99, SE = 0.17). There was also an association between having chemotherapy and increased social difficulties (using a variable including imputed missing values only) (F [7,344] = 5.95, $p<0.05$) (M = 10.45, SE = 0.76 versus M = 7.89, SE = 0.59).

Table 3 Psychosocial wellbeing by disease stage, controlling for age, gender and cancer site.

		Disease stage Mean (95% CI)		P	Partial eta²
Psychosocial wellbeing		No metastases N = 209	Metastases N = 118		
Quality of life	Physical	22.62 (21.84-23.40)	22.03 (21.00-23.06)	0.212	0.005
	Social/family	21.92 (20.92-22.92)	21.48 (20.17-22.80)	0.718	0.000
	Emotional	18.62 (17.81-19.43)	16.61 (15.55-17.68)	0.004	0.027
	Functional	18.67 (17.53-19.80)	16.84 (15.34-18.34)	0.062	0.011
	Total	81.80 (79.11-84.50)	77.04 (73.50-80.59)	0.035	0.014
Social difficulties		7.17 (6.40-7.95)	10.92 (8.71-13.14)	0.009	0.037
Anxiety		5.00 (4.17-5.82)	6.38 (5.31-7.45)	0.032	0.015
Depression		5.74 (4.71-6.77)	7.32 (5.92-8.71)	0.065	0.012
Benefit finding		35.71 (33.47-37.96)	35.36 (32.37-38.34)	0.184	0.006
Medical interactions		0.33 (0.21-0.45)	0.49 (0.33-0.65)	0.149	0.007

Co-morbidity and psychosocial wellbeing

The presence of a co-morbid condition was associated with poorer emotional quality-of-life (F [1,273] = 4.55, p<0.05) (M = 17.15, SE = 0.44 vs. M = 18.82, SE = 0.54). There was also a trend for patients with co-morbid illness to report worse social/family (F [1,272] = 2.79, p = 0.096) and overall quality of life (F [1,268] = 3.39, p = 0.067).

SES and psychosocial wellbeing

Table 4 shows the relationship between individual SES (car/home/education) and psychosocial wellbeing. There were significant linear relationships between SES and social/family quality-of-life (F [1,330] = 2.24, p<0.05), depression (F [1,310] = 6.71, p<0.05) and social difficulties (F [7,298] = 8.71, p<0.05). Those with higher SES had better quality of life, were less depressed and had fewer social difficulties. The high SES group had consistently better outcomes across many of the psychosocial wellbeing variables, as can be seen by looking at the means and confidence intervals reported in Table 4. However, there was no gradient in the SES differences across the three groups, and the 'medium' SES group did not seem distinct from either the low or high SES groups.

These analyses were repeated using the three other SES markers (Townsend index, income, and subjective SES) for comparison (Table 5). For the purpose of the ANOVA analyses, the Townsend index was divided into three equal

groups. For income, the top four groups (£40K+, see Table 2) were collapsed into one category because of small numbers in the higher income groups. This resulted in a five category variable for income. Finally, the bottom three subjective SES groups and the top three subjective SES groups were also collapsed into single categories because of small numbers (see Table 2). This resulted in a six category subjective SES variable.

The analyses using the Townsend index also found a significant difference across levels of deprivation in terms of depression (although this association became non-significant when using imputed values to take account of missing data), but no other significant differences were found. There were no significant differences in any of the psychosocial wellbeing variables according to level of income. The subjective SES score revealed a number of significant differences. The higher SES groups had better social/family, functional and overall quality of life, less anxiety and more satisfaction with medical interactions. There appeared to also be a trend for the higher SES groups to report less depression. The analyses using this marker were re-run with missing values imputed from an EM algorithm based on the other SES indicators (car, home, education, income and Townsend score). This method did not significantly alter the results. The partial eta squared statistic indicated small effect sizes for all of the significant results using any of the four SES markers.

Table 4 Psychosocial wellbeing by SES, controlling for age, gender and cancer site.

		SES Mean (95% CI)			P	Partial eta²
Psychosocial wellbeing		Low N = 62	Medium N = 133	High N = 141		
Quality of life	Physical	22.04 (20.67-23.42)	21.82 (20.80-22.85)	23.23 (22.31-24.15)	0.593	0.018
	Social/family	20.55 (18.84-22.25)	21.30 (20.07-22.53)	22.64 (21.54-23.73)	0.042	0.014
	Emotional	18.55 (17.17-19.93)	16.40 (15.37-17.43)	18.41 (17.49-19.32)	0.866	0.030
	Functional	17.99 (15.97-20.00)	16.78 (15.33-18.23)	18.93 (17.64-20.22)	0.438	0.019
	Total	79.53 (74.91-84.15)	76.22 (72.90-79.55)	83.27 (80.29-86.24)	0.180	0.036
Social difficulties		9.01 (6.66-11.36)	9.45 (7.61-11.29)	7.25 (6.74-7.76)	0.017	0.009
Anxiety		5.61 (4.17-7.06)	6.29 (5.23-7.34)	4.66 (3.72-5.60)	0.278	0.022
Depression		7.08 (5.27-8.90)	7.75 (6.50-9.00)	4.79 (3.64-5.95)	0.036	0.043
Benefit finding		37.60 (33.58-41.63)	33.96 (31.09-36.82)	34.94 (32.39-37.50)	0.272	0.006
Medical interactions		0.40 (0.20-0.61)	0.39 (0.24-0.54)	0.37(0.23-0.50)	0.780	0.001

Table 5 Differences in psychosocial wellbeing using other SES markers – controlling for age, gender and cancer site.[5]

		SES markers							
		Individual		Townsend		Income		Subjective SES	
Psychosocial wellbeing		P	Partial eta²	P	Partial eta²	P	Partial eta²	P	Partial eta²
Quality of life	Physical	0.593	0.018	0.230	0.013	0.497	0.011	0.748	0.013
	Social/family	0.042	0.014	0.259	0.011	0.733	0.011	0.016	0.063
	Emotional	0.866	0.030	0.395	0.004	0.482	0.006	0.235	0.024
	Functional	0.438	0.019	0.442	0.008	0.136	0.020	0.031	0.062
	Total	0.180	0.036	0.519	0.013	0.657	0.005	0.032	0.049
Social difficulties		0.017	0.009	0.060	0.000	0.812	0.002	0.363	0.015
Anxiety		0.278	0.022	0.348	0.012	0.582	0.004	0.018	0.053
Depression		0.036	0.043	0.053	0.010	0.180	0.012	0.074	0.036
Benefit finding		0.272	0.006	0.435	0.004	0.402	0.007	0.901	0.012
Medical interactions		0.780	0.001	0.453	0.022	0.294	0.012	0.049	0.035

[5] Analyses run with income as a three category variable (<10K, 10-20K, >20K) did not result in any significant associations. There did not appear to be a meaningful way in which to alter the subjective SES scores into a three category system, but running a system with four roughly equal sized groups (score 1-4 = 1, 5=2, 6=3, 7-10 = 4) reduced the number associations found (Social Family F (1,233) = 2.23, P = 0.226, Total quality of life F(1,229) = 1.70, P = 0.268, Medical interactions F(1,232) = 1.81, P=0.236). These changes in SES categories were considered less sensitive and were not pursued in the subsequent studies.

Interactions between SES and medical characteristics

There was a significant interaction between disease stage and individual SES for social/family quality of life (F [2,310) = 4.94, p<0.01) (partial eta squared = 0.032 i.e. small effect). High SES patients with invasive disease (M = 22.83, 95% CI = 20.91-24.76) had better quality of life than low SES patients with invasive disease (M = 17.09, 95% CI = 14.43-19.74). Figure 1 shows this relationship.

Interactions between SES and treatment types on psychosocial wellbeing were also examined. No significant interactions were found for chemotherapy or radiotherapy. SES interacted with receiving hormonal therapy on physical quality-of-life (F [2,250] = 3.96 p<0.05, partial eta squared = 0.031). Low SES patients had lower physical quality-of-life if they did not receive hormonal therapy compared to higher SES patients. The significant difference lay between the low (M = 19.13, 95% CI = 16.83-21.44) and middle SES groups (M = 22.90, 95% CI = 21.48-24.31)) who did not receive hormone therapy. Figure 2 displays this relationship and indicates that the high SES group without hormone therapy (M = 21.85, 95% CI = 20.42 – 23.28) also had higher quality of life than the lowest SES group, although comparing the confidence intervals shows that this was not a significant difference. All patients receiving hormone therapy had improved physical quality-of-life and there was no difference in physical quality-of-life between the SES groups in those receiving hormonal therapy. This suggests that the effect of receiving hormone treatment negated any SES differential in quality of life.

There were also a number of interactions between surgery and SES on psychosocial wellbeing, although it should be noted that only a small proportion of patients did not receive surgery (N = 51), meaning that, for example, only 7 patients had both low SES and did not have surgery. The interaction analyses showed that high SES patients without surgery had higher emotional quality-of-life than lower SES patients without surgery (F [2,323] = 3.10, p<0.05, partial eta squared = 0.019) (Figure 3A). The significant difference was between the high (M = 20.58, 95% CI = 18.67-22.59) and medium SES groups (M = 16.92, 95% CI = 15.17-18.67) although the same pattern was observed for the low SES groups as well (M = 17.43, 95% CI = 14.12-20.74). Patients in the 'low' and 'medium' SES groups and who had surgery seemed to show a slight improvement in emotional quality-of-life compared to those who did not have surgery, whereas high SES patients who had surgery had lower quality-of-life than high SES patients who did have surgery. This interaction meant that low and high SES patients who had surgery had comparable levels of emotional quality-of-life.

A slightly different interaction was seen for physical and overall quality-of-life: high SES patients who do not have surgery have better physical (F [2,321] = 4.16, p<0.05, partial eta squared = 0.026) (M = 25.90, 95% CI = 23.89-27.90) (Figure 3B) and overall (F [2,318] = 3.59, p<0.05, partial eta squared = 0.023) (Figure 3C) quality-of-life than patients with lower SES. In each case the significant difference lay between the 'high' and 'medium' SES groups (Medium SES and no surgery: physical M = 21.92, 95% CI = 20.17-23.68, overall M = 78.08, 95% CI = 72.43-83.72). However the graphs also demonstrate a similar trend for the low SES group, but this group had greater variation resulting in wider

confidence intervals (low SES and no surgery: physical M = 23.00, 95% CI = 19.69-26.31, overall M = 82.55, 85% CI = 71.03-94.08). All patients who have surgery experienced reduced physical and overall quality-of-life, compared to patients that do not have surgery, but the difference according to SES group disappears.

There were no significant interactions between SES and co-morbidity on psychosocial wellbeing.

Figure 1 Disease stage, SES and Quality of Life: Social/Family

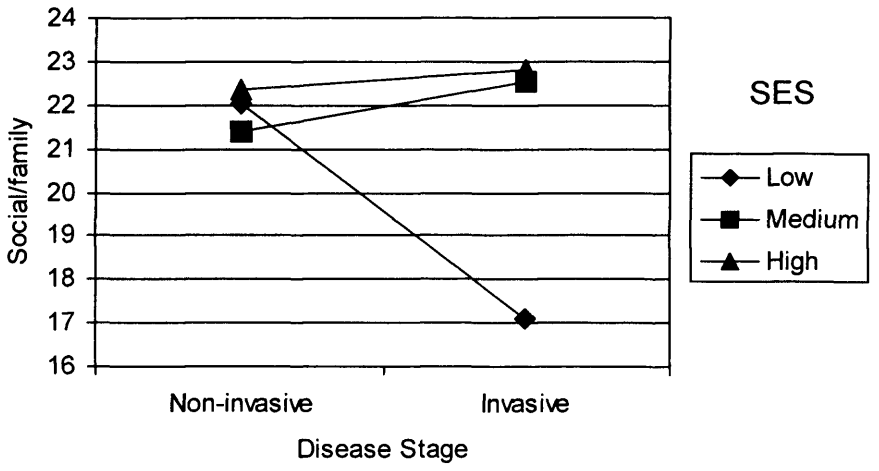


Figure 2 Hormone therapy, SES and Quality of Life: Physical

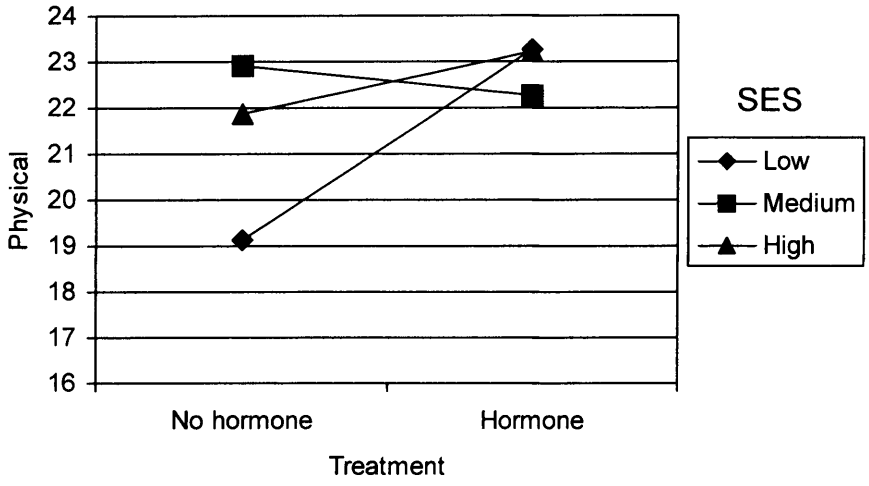


Figure 3A Surgery, SES and Quality of Life: Emotional

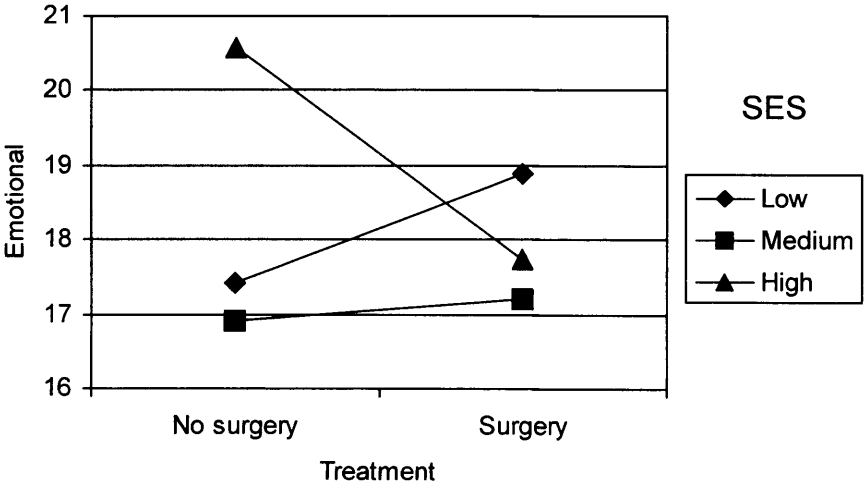


Figure 3B Surgery, SES and Quality of Life: Physical

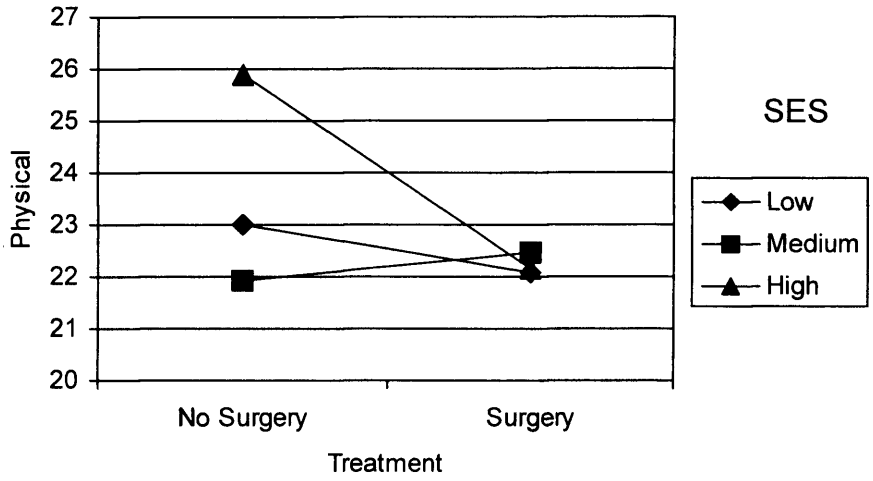
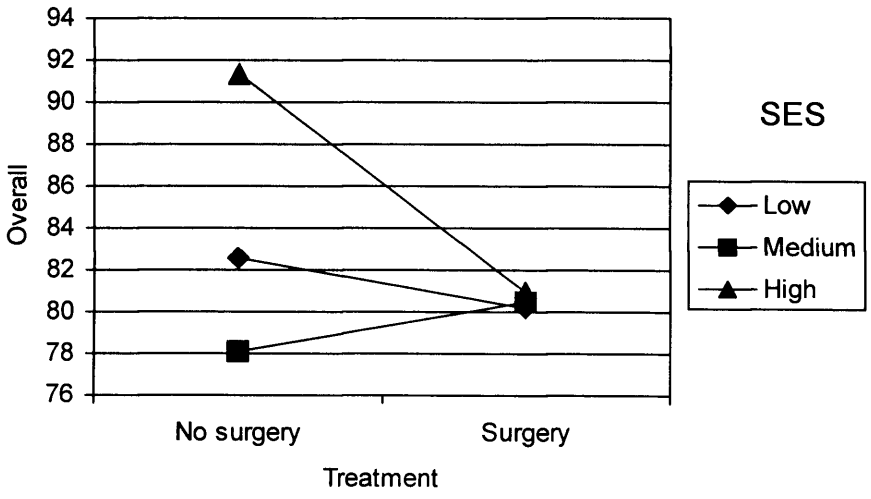


Figure 3C Surgery, SES and Quality of Life: Overall



Discussion

This study explored relationships between cancer-related stressors (disease stage, treatment type, and co-morbidity), SES and psychosocial wellbeing. I hypothesised that the presence of invasive disease, receiving chemotherapy or the presence of a co-morbid illness would be particularly stressful for lower SES patients resulting in poorer psychosocial wellbeing.

The relationship between advanced disease stage and poorer psychosocial wellbeing seen in the sample of colorectal cancer patients in Study 2 was replicated in this study. Patients with invasive disease had poorer quality of life, increased anxiety and experienced more social difficulties.

In terms of treatment type, only chemotherapy was associated with worse functional quality of life, increased dissatisfaction with medical interactions and social difficulties. Other reports have also found an association between quality of life and receiving chemotherapy (Janz et al 2005, Schover et al 1995) and one study found increased distress and dysfunction in those treated with chemotherapy that persists up to four years after diagnosis (Schover et al 1995). Surgery, radiotherapy and hormone therapy did not relate to any of the psychosocial wellbeing variables.

The analyses also showed that the presence of a co-morbid illness could have some impact on emotional, and possibly functional, quality-of-life, although the other psychosocial wellbeing variables remained unaffected. This is not a well-researched area, although one other study also reports that co-morbidity is associated with increased depressive symptoms amongst cancer patients (Kurtz et al 2002).

Four different markers of SES were used in this study. Only subjective SES showed associations with a wide range of psychosocial wellbeing variables, such that lower subjective SES related to decrease social/family, functional and overall quality of life as well as increased anxiety and dissatisfaction with medical interactions. Subjective SES could be more accurate than objective SES as it allows the individual to take into account the special circumstances of their own lives. A problem with the measure of subjective SES is that it may overlap with the psychosocial wellbeing variables e.g. depressed individuals may rate themselves lower on the subjective measure. Singh-Manoux et al (2003) used regression models with participants from the Whitehall II study and reported that the most important predictors of subjective SES were other objective SES markers (employment grade, household income, education) and although psychological functioning (hopelessness, control, mental health, vigilance, hostility, and optimism) was correlated with subjective SES it was not an independent predictor of it. This suggests that subjective SES is not a proxy for psychological functioning. However, a difficulty with using this measure in this study was that subjective SES was only assessed at the second round of data collection, meaning that it was not available for the full baseline sample which impacts the reliability of the results.

The lack of association between the Townsend index and psychosocial wellbeing variables may be because the index is based on data from the 1991 census and area characteristics could have changed. Similarly, household income may not be an accurate marker for SES in this population because a large proportion were retired, resulting in decreased income that may not truly reflect

their socio-economic position. Problems with using these two markers of SES are discussed in more detail in Chapter 3.

Individual SES was used as the primary marker because it had shown a good ability to detect SES differences in wellbeing in the sample used in Study 2. Associations between this marker and anxiety, medical interactions, physical and overall quality-of-life found in Study 2 were not replicated in this sample, although associations with social difficulties and depression were replicated. Overall, this indicates a general lack of association between the individual SES measure and psychosocial wellbeing variables in this sample. This could either be because of problems using this marker in the current sample or because there really are no effects. Only 17% of the current sample were classified in the lowest SES group. Specifically, the sample over-represented car (79.5%) and home (80.1%) owners compared to national figures (car: 77%, home: 69% (Rickards et al 2004). Nurses were responsible for recruiting to this study and were in some sense 'gatekeepers'. It is possible that this may have biased recruitment to the study with higher SES participants being over-represented. Additionally the sample is likely to include only those patients that nurses felt would be either more cognitively able to complete the questionnaire or who were generally more interested in research.

Higher SES patients were less likely to have the additional stress of a co-morbid illness. Although this may seem obvious given the higher rates of ill health amongst lower SES groups, there is little literature that has explored this topic. One study that examined this topic in a mixed-sample of cancer patients (breast, lung, colorectal, prostate, stomach) also found an association between lower SES

and increased co-morbidity, particularly for heart or vascular disease (Schrijvers et al 1997). Apart from the possible implications for survival, the additional stress of a co-morbid illness might be expected to decrease psychosocial wellbeing. However, the evidence from this study showed only weak associations between co-morbidity and lower quality of life.

Higher SES patients were also more likely to have had radiotherapy. Two studies looking at the use of palliative (Huang et al 2001) and adjuvant (Paszat et al 1998) radiotherapy in Canadian breast cancer patients also report that high SES patients are more likely to receive these treatments. Other studies find no such association, including one study of breast cancer patients in Scotland (Macleod et al 2000) and one study with prostate patients in the US (Krupski et al 2005). These conflicting results imply variation in the implementation of treatment strategies that could reflect both geographic and provider differences that in turn influence the accessibility of radiotherapy for patients from different socio-economic backgrounds. One suggestion is that patients from higher SES backgrounds are more likely to demand radiotherapy (Huang et al 2001), possibly related to an overall higher level of participation in treatment decisions also seen in the higher rates of high SES participants enrolled in clinical trials (Gross et al 2005).

These differences in exposure to cancer-related stressors did not affect the wellbeing of different SES groups as no significant interactions between SES and radiotherapy or co-morbidity on psychosocial wellbeing were found. There was a significant interaction between SES and disease stage on social/family quality-of-life in this sample. High SES patients with invasive disease had better quality of

life than low SES patients with invasive disease. The interaction found in the previous study regarding the effect of SES and disease stage on anxiety was not replicated. The interaction effects with disease stage may not be consistent and the effects are small.

There were interactions between surgery and SES on quality of life. The effect of treatment appeared to flatten the SES disparities in quality of life. Although differences in quality of life may exist prior to treatment, the effect of having surgery for cancer is equally good or bad regardless of SES. However, because only small numbers of patients did not receive surgery, (for example, only 7 patients had both low SES and did not have surgery) this limits the strength of the conclusions that can be drawn. The evidence from the interaction analyses suggests that the hypothesis that differences in psychosocial wellbeing according to level of SES would widen in situations of severe stress, such as an invasive cancer diagnosis, or when undergoing different treatments, is not demonstrated. On the contrary, the evidence from the interactions between SES and surgery on psychosocial wellbeing indicates that undergoing treatment for cancer may lessen the differences in psychosocial wellbeing according to SES.

There were a number of limitations to this study. The first was the recruitment strategy that may have introduced a source of bias, as discussed. It also meant that information regarding non-responders could not be accessed in order to assess the extent of the bias. Another issue was that the collection of information regarding medical characteristics from patient's medical files could not be completed due to lack of co-operation from participating hospitals. Reasons cited for not allowing access to records were largely due to limited time resources

for staff to complete research protocols. Medical record data could be supplemented by self-report measures for a number of variables, but a large proportion of missing data regarding co-morbidity still remained.

A more fundamental problem was that the study was underpowered to detect small effect sizes. Post-hoc power analyses using g-power software revealed that the power to detect a small effect size (0.10), with 3 groups of SES, an alpha of 0.05 and sample size of 352, is only 0.4. Good power of 0.8 is only maintained for effect sizes of 0.17 and above. The majority of the analyses in this study also included elements of missing data. Although the missing data in the psychosocial wellbeing variables was unrelated to SES, it did further reduce the sample size and consequently weaken the power. Particularly, the interaction analyses were probably not sufficiently powered to detect any small effects. This means that a definite conclusion that there were no interaction effects cannot be reached.

The results did confirm that the presence of invasive disease was an added psychosocial burden and that to some extent both co-morbidity and chemotherapy could also lead to worse psychosocial adjustment. But the results also showed that these differences in adjustment according to medical characteristics did not increase greatly with lower SES and any differences in exposure to cancer-related stressors did not have a significant impact on psychosocial wellbeing. Further analyses of the longitudinal aspect of this dataset will reveal if SES has an impact on psychosocial adjustment to cancer over time.

CHAPTER 9

Study 5: Socioeconomic status differences in psychosocial resources amongst cancer patients

Introduction

In Study 4, the relationship between SES and psychosocial wellbeing in cancer patients was explored. The results showed some evidence of poorer wellbeing in lower SES groups and patients with more invasive disease, but no evidence that lower SES groups were especially vulnerable to invasive disease. In Chapter 1, I had proposed that SES would relate to the distribution of psychosocial resources that are required to adapt successfully to a stressful situation. In this Chapter I will explore this idea using the same dataset as used in Study 4.

A number of individual psychological characteristics have been hypothesised to influence reactions to stress. As discussed in Chapter 1, a sense of personal control and higher levels of optimism relate to better psychosocial adjustment during times of stress, such as experiencing a physical illness. Levels of perceived social support and the closely related resource of disclosure, or the ability to communicate openly about difficulties within the family also play a role. Finally, choice and use of different coping strategies may influence subsequent psychological wellbeing.

These resources have also been implicated in the relationship between SES and wellbeing. Whilst there is an established link between personal control and SES, the relationships between SES and optimism or social support and

disclosure are less clear (see Chapter 1). The relationships between coping strategies and SES have never been explored in any great detail. Taylor and Seeman (1999) propose coping strategies as a potential candidate in the mediational chain between SES and psychosocial wellbeing. They cite a personal communication from Charles Carver that avoidant coping strategies may be higher in lower SES groups, but report no examples of published research in this area. The action of coping strategies on SES may be via their relationship to other resources such as control, optimism and social support, as discussed in Chapter 1, or because of a more direct relationship to SES. This study will explore whether coping strategies are directly associated with SES.

The aim of this study was to look at the distribution of psychosocial resources (control, optimism, social support, disclosure and coping strategies) according to SES. The relationships between psychosocial resources and wellbeing will also be examined. Finally, the combined influence of SES and resources on wellbeing will be explored. I hypothesised that lower SES would relate to lower levels of psychosocial resources and that lower resources would relate to poorer psychosocial wellbeing.

Hypotheses

1. High SES will be associated with greater mastery, optimism and social support. Coping strategies might differ by SES.
2. Psychosocial resources (mastery, optimism, social support, and use of effective coping strategies) will be associated with psychosocial wellbeing (quality of life, depression, anxiety, social difficulties, benefit finding, and medical interactions).
3. SES and resources will predict psychosocial wellbeing.

Method

Participants, Design and Procedure

The methods used in the present study are identical to those described in Study 4 and so are not repeated here. The sample consisted of 352 colorectal, breast and prostate cancer patients. Participants completed a self-report questionnaire covering a range of psychosocial wellbeing outcomes and resources: quality of life, social problems, experience of medical care, anxiety, depression, benefit finding, social support, disclosure, mastery, optimism and coping strategies. Demographic information included ethnicity, gender, and socio-economic status (SES). Surveys were completed at two time points: 1-3 months post-diagnosis and 9-12 months post diagnosis. Data for this report were taken from the baseline of the study.

Measures

Psychosocial Resources

Personal Control

Control was assessed using the Pearlin Mastery Scale (Pearlin & Schooler 1978). Mastery is the extent to which a person perceives themselves to be in control of events or ongoing situations and reflects the perception of the ability to manage them. The scale consists of 7 items. An example item is: "I can do just about anything I really set my mind to do." There are five response categories ranging from 'strongly disagree' to 'strongly agree'. Participants are asked to respond according to how they generally feel. Items are scored one to five, with appropriate items reversed scored. This results in a scale with a range from 7 to 35. Higher scores indicate more feelings of mastery.

Optimism

Optimism was assessed using the Life Orientation Test-Revised (LOT-R) (Scheier et al 1994). This is a measure of dispositional optimism i.e. a personality variable, used to assess individual differences in generalised optimism. Participants were asked to respond according to how they generally feel. There are six items in the scale, with five response options from 'strongly disagree' to 'strongly agree'. An example item is: "Overall, I expect more good things to happen to me than bad". Responses are scored one to five so that high values relate to increased optimism. The scale range is from 6 to 30.

Social Support

Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al 1988). The MSPSS is a measure of the subjective assessment of social support adequacy. It is a 12-item scale with three subscales (4 items each) examining support from family (e.g. 'my family really tries to help me'), friends (e.g. 'I can count on my friends when things go wrong'), and significant other (e.g. 'There is a special person who is around when I am in need'). Participants are asked how much they agree or disagree with each statement. A five-point response rating scale was used from 'strongly disagree' to 'strongly agree'. The scale range is 1 to 60 with higher scores indicating better support.

Disclosure

Disclosure was measured using the Openess to Discuss Cancer in the Family scale (ODCF) (Mesters et al 1997). This scale assessed the amount of open communication about cancer in the family. This was originally a nine-item scale. A modified five-item version of this scale was used in this study. Four items that referred specifically to a partner or child were excluded because they did not apply to all participants. Participants are asked to indicate for each item how much they agree or disagree with the statement. There are four response options: 'strongly agree', 'agree', 'disagree', 'strongly disagree'. Items are scored 1-4 with a higher score indicating greater openness. The items in the scale refer to both self-disclosure of the disease (e.g. I talk as little as possible about my illness because I don't want to make my family uneasy) and the family's ability to talk about the disease (e.g. Talking about my emotions related to my illness upsets my

family). The scale in this study had reasonable internal reliability (α=0.67), that was not improved by deleting any one item from the scale.

Coping strategies

Coping was measured using items from the Brief Cope (Carver 1997). The Brief COPE is a 28 item scale consisting of 14, two-item subscales that measure different ways of coping: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame. In this study, sub-scales referring to social support (both emotional and instrumental) were removed as similar constructs were measured elsewhere in the questionnaire. This resulted in a 24-item scale. Participants are asked to rate how much they have been using each coping strategy on a four-point scale. For example: "I've been turning to work or other activities to take my mind off things" (active coping) with the response options: 'I haven't been doing this at all', 'I've been doing this a little bit', 'I've been doing this a medium amount', 'I've been doing this a lot'. Items are scored 1 to 4 and sub-scale scores are calculated by summing the two items that form the scale. Therefore each sub-scale has a score from 1 to 8. The subscales of the Brief COPE have good internal reliability (Carver 1997).

Socio-economic status

There were four markers of socio-economic status: individual SES (3 categories), Townsend Index (3 categories), income (5 categories) and subjective SES (6 categories), described in detail in the previous chapter.

Psychosocial wellbeing

Psychosocial wellbeing was assessed using a number of questionnaire scales described in the previous chapter: quality of life, social difficulties, anxiety, depression and medical interactions and benefit finding.

Analyses

Data were analyzed using analysis of variance with SES as the independent variable, and age, gender and cancer sites as control variables. Psychosocial resources: control, optimism, social support, disclosure, and coping strategies were the dependent variables. The analyses were carried out using four different SES markers (individual SES [car/home/education], Townsend score, income and subjective SES). The relationships between psychosocial resources and psychosocial wellbeing were examined using pearson correlations. Finally, a series of hierarchical regression analyses were run to examine the contribution of both SES and resources on psychosocial wellbeing.

Intracluster correlation coefficients for the effect of hospital sites were calculated for all of the dependent variables. Most of the dependent variables had small intracluster correlations (range: 0.001-0.05) (Hox 2002). The coping strategy 'venting' was approaching a medium-sized correlation (0.09) and any analyses involving this variable included adjustment for clustering due to hospital site.

I hypothesized that lower SES would be associated with lower control, optimism and social support. I expected that control, optimism, social support, disclosure and coping strategies would be correlated with better psychosocial wellbeing.

Results

Table 1 shows the relationships between psychosocial resources and the individual SES marker. Higher SES was associated with increased control (F [1,322] = 3.34, $p<0.05$) with a clear gradient in control across the three SES groups. A similar pattern was seen for optimism with increasing optimism associated with higher levels of SES (F [1,317] = 5.67, $p<0.01$). The association between individual SES and control and optimism was also found using the measures of income and subjective SES (see Table 2). This suggests a robust relationship.

There was no association between social support and disclosure and SES. The means in Table 1 do show that the low SES group had consistently lower social support and the high SES group reported more openness to discuss cancer in the family (disclosure), but these differences were not significant and the effect sizes were small.

Two coping strategies were also associated with SES: substance use (F [1,328] = 7.18, $p<0.05$) and planning (F [1,323] = 2.74, $p<0.05$). Lower SES groups were more likely to use alcohol or drugs to help them cope with their illness. Higher SES groups were more likely to think about what steps needed to be taken to cope with the illness. The association between individual SES and substance use was not found using any of the other SES markers, but income was also associated with the use of 'planning' coping strategies. The Townsend index was not associated with any of the psychosocial resources.

Table 1 Psychosocial resources by individual SES controlling for age, gender and cancer site

		SES			P value	Partial eta²
Psychosocial resources		Low N = 62	Medium N = 133	High N = 141		
Mastery		23.45 (21.31-25.60)	24.38 (22.92-25.84)	26.04 (24.77-27.31)	0.041	0.022
Optimism		19.75 (18.06-21.43)	20.82 (19.57-22.06)	22.59 (21.53-23.66)	0.005	0.035
Social support	Significant other	16.67 (15.42-17.92)	18.14 (17.27-19.01)	17.84 (17.07-18.61)	0.115	0.008
	Family	17.22 (16.27-18.17)	18.00 (17.33-18.67)	17.91 (17.31-18.50)	0.225	0.004
	Friends	16.39 (15.29-17.49)	16.69 (15.92-17.47)	16.95 (16.27-17.63)	0.389	0.001
	Total	50.09 (47.31-52.86)	52.98 (51.14-54.83)	52.71 (51.09-54.34)	0.108	0.007
Disclosure	Openness within family	12.71 (11.44-13.99)	12.65 (11.89-13.41)	13.69 (12.99-14.40)	0.184	0.015
Coping strategies	Self-distraction	4.09 (3.46-4.72)	4.25 (3.80-4.70)	4.62 (4.22-5.02)	0.167	0.005
	Denial	2.71 (2.18-3.25)	3.38 (3.01-3.76)	2.83 (2.49-3.17)	0.722	0.027
	Substance use	4.85 (4.53-5.17)	4.13 (3.89-4.36)	4.44 (4.23-4.65)	0.035	0.044
	Behavioural disengagement	2.38 (2.08-2.67)	2.48 (2.27-2.68)	2.11 (1.93-2.29)	0.129	0.024
	Venting	3.22 (2.45-3.99)	3.21 (2.98-3.44)	3.26 (3.07-3.46)	0.895	0.000
	Self-blame	2.61 (2.22-3.00)	2.49 (2.20-2.77)	2.52 (2.26-2.77)	0.679	0.002
	Active	4.71 (4.06-5.36)	4.48 (3.99-4.97)	5.17 (4.76-5.59)	0.239	0.015
	Positive reframing	4.36 (3.74-4.99)	3.84 (3.40-4.28)	4.62 (4.22-5.01)	0.506	0.016
	Planning	4.07 (3.43-4.72)	4.31 (3.87-4.76)	4.84 (4.44-5.24)	0.046	0.017
	Humour	4.05 (3.36-4.74)	4.04 (3.54-4.53)	3.86 (3.41-4.31)	0.640	0.003
	Acceptance	7.26 (6.64-7.66)	6.26 (5.89-6.62)	6.66 (6.33-6.98)	0.107	0.026
	Religion	4.48 (3.76-5.19)	3.33 (2.82-3.85)	4.22 (3.75-4.68)	0.545	0.021

Table 2 Differences in psychosocial resources using other SES markers – controlling for age, gender and cancer site.

		SES markers							
		Individual		Townsend		Income		Subjective	
Psychosocial resources		P	Partial eta²	P	Partial eta²	P	Partial eta²	P	Partial eta²
Mastery		0.041	0.022	0.230	0.007	0.009	0.034	0.036	0.090
Optimism		0.005	0.035	0.125	0.009	0.008	0.041	0.015	0.087
Social support	Significant other	0.115	0.008	0.813	0.003	0.695	0.007	0.164	0.023
	Family	0.225	0.004	0.437	0.002	0.282	0.005	0.153	0.048
	Friends	0.389	0.001	0.906	0.000	0.764	0.009	0.061	0.018
	Total	0.108	0.007	0.797	0.000	0.963	0.008	0.128	0.012
Disclosure	Openness within family	0.184	0.015	0.471	0.003	0.104	0.030	0.202	0.024
Coping strategies	Self-distraction	0.167	0.005	0.834	0.003	0.490	0.021	0.122	0.060
	Denial	0.722	0.027	0.344	0.019	0.326	0.011	0.084	0.045
	Substance use	0.035	0.044	0.605	0.007	0.260	0.039	0.567	0.017
	Behavioural disengagement	0.129	0.024	0.755	0.001	0.346	0.007	0.539	0.020
	Venting	0.895	0.000	0.411	0.005	0.339	0.016	0.411	0.026
	Self-blame	0.679	0.002	0.332	0.006	0.226	0.020	0.342	0.015
	Active	0.239	0.015	0.611	0.003	0.110	0.013	0.068	0.030
	Positive reframing	0.506	0.016	0.876	0.004	0.433	0.008	0.460	0.039
	Planning	0.046	0.017	0.959	0.000	0.017	0.033	0.220	0.056
	Humour	0.640	0.003	0.602	0.009	0.344	0.008	0.213	0.028
	Acceptance	0.107	0.026	0.158	0.011	0.535	0.016	0.470	0.031
	Religion	0.545	0.021	0.286	0.006	0.083	0.010	0.844	0.020

Disclosure was a poorly completed scale with N = 50 having missing data. The missing data for optimism and control, although small amounts, were related to SES such that low SES groups were less likely to complete these items. Missing data in this sample was also important because the study was underpowered, as discussed in the previous chapter. However, imputing missing values for each variable, using the subject mean for each subscale if at least half of the items had been completed, did not alter the results in any meaningful way.

The relationship between psychosocial resources and psychosocial wellbeing was explored using pearson correlations (Table 3). Increased control and optimism related to better quality of life (control: $r = 0.38$, $df = 317$, $p<0.001$, optimism: $r = 0.43$, $df = 321$, $p<0.001$), less anxiety (control: $r = -0.44$, $df = 319$, $p<0.001$, optimism: $r = -0.47$, $df = 322$, $p<0.001$), less depression (control: $r = -0.46$, $df = 305$, $p<0.001$, optimism: $r = -0.43$, $df = 308$, $p<0.001$), and fewer social difficulties (control: $r = -0.18$, $df = 291$, $p<0.05$, optimism: $r = -0.18$, $df = 293$, $p<0.05$). Control was also correlated with medical interactions such that increased control related to less dissatisfaction with medical care ($r = -0.19$, $df = 319$, $p<0.01$).

Table 3 The relationships between psychosocial resources and wellbeing

		Psychosocial wellbeing – Pearson r									
		Quality of Life					Social Difficulties	Anxiety	Depression	Benefit Finding	Medical Interactions
Psychosocial Resources		Emotional	Functional	Physical	Social/ family	Total					
Mastery		0.30***	0.33***	0.24***	0.21**	0.38***	-0.18*	-0.44***	-0.46***	0.11	-0.19**
Optimism		0.36***	0.32***	0.22**	0.36***	0.43***	-0.18*	-0.47***	-0.43***	0.09	-0.03
Social Support	Family	0.12	0.21**	0.18*	0.53***	0.38***	-0.26***	-0.23***	-0.27***	0.24***	0.01
	Friends	0.06	0.12	0.02	0.43***	0.24***	-0.01	-0.12	-0.19**	0.24***	-0.10
	Significant other	0.07	0.12	-0.07	0.28***	0.15*	-0.00	-0.16*	-0.21**	0.19**	-0.01
	Total	0.10	0.17*	0.03	0.49***	0.29***	-0.09	-0.20**	-0.26***	0.26***	-0.05
Disclosure	Openness	0.10	0.24**	0.11	0.35***	0.30***	-0.13	-0.36***	-0.33***	0.02	-0.14
Coping strategies	Self-distraction	-0.22***	-0.12*	-0.14**	-0.01	-0.16**	0.17**	0.25***	0.18***	0.25***	0.09
	Denial	-0.29***	-0.17**	-0.12*	-0.06	-0.21***	0.06	0.36***	0.26***	0.14*	0.15**
	Substance use	.021	0.04	-0.09	0.10	0.03	-0.02	-0.09	0.01	0.25***	-0.04
	Behavioural Disengagement	-0.28***	-0.12*	-0.12*	-0.10	-0.19***	0.18**	0.27***	0.27***	-0.05	0.24***
	Venting	-.035***	-0.29***	-0.35***	-0.15**	-0.38***	0.40***	0.40***	0.43***	0.17**	0.13*
	Self-blame	-0.27***	-0.23***	-0.17**	-0.05	-0.25***	0.29***	0.29***	0.31***	-0.03	0.19***
	Acceptance	0.12*	0.11*	-0.11*	0.16**	0.11*	0.01	-0.13*	-0.04	0.26***	-0.15**
	Active	-0.12*	0.03	-0.12*	0.05	-0.05	0.13*	0.13*	0.03	0.35***	0.03
	Positive reframing	-0.06	0.03	-0.18***	0.15**	-0.01	0.16**	0.12*	0.05	0.51***	0.05
	Planning	-0.22***	-0.11*	-0.17**	-0.05	-0.20***	0.19***	0.19***	0.19***	0.21***	0.09
	Humour	-0.07	0.01	-0.14*	0.09	-0.03	0.19***	0.04	-0.02	0.15**	-0.03
	Religious	-0.10	-0.01	-0.13*	0.08	-0.04	0.10	0.11	0.08	0.40***	0.06

*** Correlations is significant at the 0.001 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 4 Summary of multiple regression analyses showing the associations between SES, psychosocial resources and wellbeing [a]

Quality of life			B (SE)	Beta	t	P (t)
Model 1	SES		1.833 (1.061)	0.092	1.728	0.085
$R = 0.230$ $R^2 = 0.053$ Adj $R^2 = 0.008$ $F(4,347) = 4.85$, $P<0.001$						
Model 2[b]	Mastery		0.397 (0.138)	0.161	2.870	0.004
	Optimism		0.488 (0.164)	0.168	2.987	0.003
	Social Support		0.311 (0.089)	0.166	3.507	0.001
	Disclosure		0.556 (0.248)	0.110	2.244	0.026
	Coping	Venting	-6.612 (1.669)	-0.224	3.962	0.001
		Planning	-6.246 (1.952)	-0.174	3.200	0.002
$R = 0.595$ $R^2 = 0.354$ Adj $R^2 = 0.315$ $F(20,331) = 9.06$, $P<0.001$						
Social Difficulties			B (SE)	Beta	t	P (t)
Model 1	SES		-10.21 (0.552)	-0.95	1.903	0.058
$R = 0.408$ $R^2 = 0.166$ Adj $R^2 = 0.157$ $F(4,347) = 17.32$ $P<0.001$						
Model 2[b]	Mastery		-0.252 (0.079)	-0.184	3.172	0.002
	Social Support		-0.145 (0.051)	-0.140	2.859	0.005
	Coping	Venting	2.378 (0.958)	0.145	2.482	0.014
		Self-blame	2.161 (0.900)	0.125	2.401	0.017
$R = 0.555$ $R^2 = 0.308$ Adj $R^2 = 0.266$ $F(20,331) = 7.360$, $P<0.001$						
Anxiety			B (SE)	Beta	t	P (t)
Model 1	SES		-0.659 (0.325)	-0.108	2.030	0.043
$R = 0.255$ $R^2 = 0.065$ Adj $R^2 = 0.054$ $F(4,347) = 6.023$, $P<0.001$						
Model 2[b]	Mastery		-0.144 (0.041)	-0.190	3.491	0.001
	Optimism		-0.149 (0.049)	-0.166	3.041	0.003
	Disclosure		-0.249 (0.074)	-0.159	3.362	0.001
	Coping	Denial	0.955 (0.423)	0.108	2.259	0.025
		Venting	1.761 (0.499)	0.194	3.532	0.001
$R = 0.625$ $R^2 = 0.391$ Adj $R^2 = 0.354$ $F(20,331) = 10.632$, $P<0.001$						
Depression			B (SE)	Beta	t	P (t)
Model 1	SES		-0.838 (0.372)	-0.121	2.249	0.025
$R = 0.206$ $R^2 = 0.043$ Adj $R^2 = 0.032$ $F(4,347) = 3.861$, $P<0.01$						
Model 2[b]	Mastery		-0.172 (0.048)	-0.199	3.584	0.001
	Optimism		-0.165 (0.057)	-0.162	2.913	0.004
	Social support		-0.074 (0.031)	-0.114	2.424	0.016
	Disclosure		-0.232 (0.086)	-0.131	2.706	0.007
	Coping	Venting	2.512 (0.577)	0.244	4.353	0.001
$R = 0.605$ $R^2 = 0.366$ Adj $R^2 = 0.327$ $F(20,331) = 9.538$, $P<0.001$						
Benefit Finding			B (SE)	Beta	t	P (t)
Model 1	SES		-0.840 (0.888)	-0.052	0.947	0.344
$R = 0.121$ $R^2 = 0.015$ Adj $R^2 = 0.003$ $F(4,347) = 1.284$, NS						
Model 2[b]	Social Support		0.263 (0.079)	0.172	3.331	0.001
	Coping	Religion	4.331 (1.295)	0.181	3.345	0.001
		Positive reframing	7.615 (1.697)	0.269	4.487	0.001
$R = 0.488$ $R^2 = 0.238$ Adj $R^2 = 0.192$ $F(20,331) = 5.171$, $P<0.001$						
Medical Interactions						
Model 1	SES		-0.71 (0.047)	-0.082	1.492	0.136
$R = 0.089$ $R^2 = 0.008$ Adj $R^2 = 0.004$ $F(4,347) = 0.689$, NS						
Model 2[b]	Mastery		-0.19 (0.007)	-0.179	2.736	0.007
	Coping	Behav. Disengage.	0.221 (0.091)	0.137	2.428	0.016
$R = 0.350$ $R^2 = 0.123$ Adj $R^2 = 0.070$ $F(20,331) = 2.311$ $P<0.001$						

(a) Age, gender and cancer type are included as control variables in all models
(b) Only variables where $P(t)<0.05$ are reported in the table

Higher levels of social support were related to increased quality of life (r = 0.29, df = 314, p<0.001) and particularly to increased social/family quality-of-life (r = 0.49, df = 318, p<0.001). More perceived social support was also correlated with decreased anxiety (r = -0.20, df = 316, p<0.01) and depression (r = -0.26, df = 303, p<0.001) and higher levels of benefit finding (r = 0.26, df = 314, p<0.001). The associations between disclosure and the psychosocial wellbeing variables were largely similar to those found for social support, except there was no relationship between disclosure and benefit finding.

Many of the coping strategies were related to poorer quality of life and higher anxiety, depression or social difficulties. Particularly self-distraction, behavioural disengagement, venting, self-blame and planning were associated with each of these wellbeing variables such that use of the strategy related to poorer wellbeing. However, these same coping strategies were also related to increased benefit finding. Only acceptance was related to better psychosocial wellbeing. Acceptance was related to increased quality of life (r = 0.11, df = 333, p<0.05), less dissatisfaction with medical interactions (r = -0.15, df = 335, p<0.01) and decreased anxiety (r = -0.13, df = 335, p<0.01).

Hierarchical regression analyses explored the contribution of both SES and resources on wellbeing. SES was entered in a first block (model 1) and resources added in a second block (model 2). The results of these analyses are displayed in Table 4. The F values indicate that there were significant relationships between SES and quality of life, social difficulties, anxiety and depression. However, in each case the adjusted R^2 for the models that included

only SES were low (range: 1-16%), demonstrating a poor fit. The models that included psychosocial resources were significantly associated with all of the wellbeing variables. In each case there was an increase in the adjusted R^2 values compared to the first step of the regression which only included SES, but the proportion of variance explained was still relatively low (range: 7-35%).

The relationships between SES, resources and wellbeing were in the directions expected based on the univariate analyses. The beta weights gave some indication of which variables had the greatest effect on wellbeing. 'Venting' had the strongest association with quality of life, anxiety and depression, while 'mastery' had the highest beta weights in analyses predicting social difficulties and medical interactions. 'Benefit finding' was most highly associated with positive reframing.

Discussion

This study explored the relationships between SES and psychosocial resources, between psychosocial resources and psychosocial wellbeing and the combined contribution of SES and resources on wellbeing. I hypothesised that lower SES would be associated with decreased mastery, optimism, social support and disclosure. I also proposed that there could be an association between SES and choice of coping strategies. I expected that psychosocial resources would be related to levels of psychosocial wellbeing and that the combination of SES and resources would successfully predict wellbeing.

The literature consistently reports an association between personal control and SES (Lachman & Weaver 1998, Marmot et al 1997, Pudrovska et al 2005). This effect was replicated in this sample with higher SES patients reporting increased control. An association between optimism and SES, such that high SES was associated with increased optimism, was also found in this study. Taylor and Seeman (1999) discuss four unpublished datasets that find similar relationships between SES and optimism that are confirmed by the results of this study.

The evidence reviewed in Chapter 1 suggested that there would also be an association between social support and SES, with lower SES groups reporting less social support. Additionally, I proposed that disclosure and open communication within the family, a construct closely related to social support, may also have been related to SES. The results of this study found no relationship between either social support or disclosure and SES, although the results from Study 2 did show a significant association between SES and social support. Looking at the mean values for social support and disclosure in relation to SES in this sample suggests that a significant association between SES and social support may have gone undetected due to low power, as discussed in the previous chapter. The mean values implied that lower SES could be associated with less social support and disclosure. The partial eta squared values implied that any undetected effect was likely to be small. Alternatively, there may be no association between perceived social support and SES, rather other aspects of

social resources, such as size of social networks, could be more important in relation to SES (Stansfeld 1999).

There was also little evidence that coping strategies were directly related to SES. The most likely candidates were substance use and planning. The association with substance use may reflect the behavioural association of increased alcohol or cigarette consumption among lower SES groups rather than any cognitive aspect relating to coping and SES. As regards 'planning', one characteristic of Taylor's (1998) construct of 'reactive responding' (see Chapter 1) in lower SES groups is that it will be characterised by 'On-Line Responding/On-Line Planning'. She suggests that low SES groups may have little opportunity for anticipatory planning and that what planning occurs may be 'on-line' in response to environmental demands. The results here seem to support this idea as only the higher SES participants reported planning what steps to take in response to their illness.

There was some evidence, therefore, that psychosocial resources were distributed according to SES. The importance of psychosocial resources for psychosocial wellbeing was also confirmed by the correlation analyses. The associations between control and optimism and psychosocial wellbeing were particularly strong and consistent. Notably these were also the resources that were related to SES.

The correlational analyses also showed that many of the coping strategies were related to poorer psychosocial wellbeing in terms of quality of life, depression or anxiety, and social difficulties. However, the same coping

strategies appeared to be positively related to benefit finding, although these associations were not present in the multivariate regression analyses, where only 'positive reframing' and 'religious' coping were associated with benefit finding.

The regression analyses also revealed that 'venting' was important for determining wellbeing. 'Venting' referred to allowing negative feelings and emotions to be expressed. In this study, increased use of 'venting' led to decreased wellbeing. The existing literature also implies that venting may have adverse effects on psychosocial adjustment amongst cancer patients (Compas et al 1999, Deimling et al 2005). Other studies also support the beneficial effect of some coping strategies (e.g. humour and focusing on the positive) (Carver et al 1993, Dunkel-Schetter et al 1992) that was not confirmed in these analyses. The finding that approach or positively-valence strategies (active, planning, humour, religion) were related to more distress in the correlation analyses is perhaps surprising. One possible explanation is that approach or problem-solving strategies were not beneficial in these circumstances because the cancer diagnosis was inherently uncontrollable or unchangeable. The finding that 'acceptance' (characterised as facing reality and learning to live with the illness, rather than trying to change the situation) was the strategy associated with wellbeing in the correlation analyses supports this view. Alternatively it may be that the relationship works in the opposite direction, i.e. decreased psychosocial wellbeing elicits increased use of a number of coping strategies to try to improve or change the situation.

The regression analyses showed that including resources in the model increased the proportion of variance explained in wellbeing considerably compared to models that only included SES. However, the adjusted R^2 figures were still relatively low, leading to the conclusion that other unmeasured factors must play a major role in determining psychosocial wellbeing. There are a number of variables that were not assessed within the scope of this study, but which could be considered as candidates for influencing wellbeing. These include personality traits such as neuroticism (de Jonge et al 2004) and self-esteem (Penninx et al 1998), past history of mental illness (Burgess et al 2005) and other physical symptoms or side-effects, such as cancer-related fatigue (Barsevick et al 2006).

Obviously the limitations of the study were the same as those discussed in Study 4, i.e. the recruitment strategy, resulting in possible bias in the types of people included in the sample, and the relatively low power, affecting the ability to draw definite conclusions. However, two of the main hypotheses: that psychosocial resources would relate to SES, and that resources would relate to psychosocial wellbeing were largely supported. Particularly control and optimism were lower among lower SES groups and these resources were also significantly and consistently related to a number of psychosocial wellbeing outcomes. The final hypothesis, that the combination of SES and resources would successfully predict psychosocial wellbeing, was also supported, although the proportion of variance explained in wellbeing was not high.

CHAPTER 10

Study 6: Socioeconomic status differences in psychosocial adjustment to cancer over time

Introduction

Study 1 explored psychological adjustment to bowel cancer screening over time (from pre to post-screening) and found no evidence of differential adjustment by level of SES. The stressor explored in Study 1, that of cancer screening, was relatively minor compared to the experience of receiving a cancer diagnosis. It would be useful to explore whether the findings from Study 1 are consistent across other situations or if increases in the level of stress experienced resulted in differential psychosocial adjustment over time according to SES. The dataset described in Studies 4 and 5 had a longitudinal component and provided an opportunity to explore psychosocial adjustment to receiving a cancer diagnosis by level of SES over time.

The cross-sectional results in Study 4 had also shown that there were very few SES differences in psychosocial wellbeing at 1-3 months post-cancer diagnosis. In some ways this was contradictory to evidence from general population samples that show that low SES groups experience poorer psychosocial wellbeing overall compared to high SES groups. It is possible that the initial shock of receiving a cancer diagnosis diminishes SES differences in psychosocial wellbeing rather than increasing the differences. If this is the case, then SES differences in wellbeing may re-emerge over time as treatment is

completed and patients adjust to their new situation. The results from Study 2, where SES differences in psychosocial wellbeing amongst bowel cancer patients were found, lent some support to this hypothesis. The cancer patients in Study 2 were on average 257 days post-diagnosis when they completed a research survey, whereas patients in Study 4 were only 66 days post-diagnosis on average. However, patients in Study 2 were not selected according to a fixed-point post-diagnosis, but rather were sampled at any time from one month to one year post-diagnosis.

The aim of the present study was to examine if there are SES differences in psychosocial wellbeing at 9-12 months after receiving a cancer diagnosis. In general, cancer patients appear to experience more psychosocial difficulties around the time of diagnosis compared to later in the course of their illness, as discussed in Chapter 2. Therefore, I expected that there would be an increase in psychosocial wellbeing over time and that higher SES groups would experience greater improvements in psychosocial wellbeing compared to lower SES groups.

Hypotheses

1. SES will be associated with psychosocial wellbeing in cancer patients 9-12 months post-diagnosis. Lower SES groups will experience poorer psychosocial wellbeing than higher SES groups.
2. There will be an increase in psychosocial wellbeing amongst cancer patients over time (from 1-3 months diagnosis to 9-12 months diagnosis).

3. Increases in psychosocial wellbeing over time will differ according to SES. Higher SES groups will experience greater improvements in wellbeing compared to lower SES groups.

Method

Participants, Design and Procedure

Data for these analyses are taken from the longitudinal survey, previously described in Studies 4 and 5. Patients had received a diagnosis of breast, prostate or colorectal cancer and were recruited from nine hospital sites in and around North London, Middlesex and Essex. Participants completed a self-report questionnaire covering a range of psychosocial wellbeing outcomes and resources: quality of life, social problems, experience of medical care, anxiety, depression, benefit finding, social support, disclosure, mastery, optimism and coping strategies. Demographic information included ethnicity, gender, and socio-economic status (SES). 352 patients were recruited 1-3 months post-diagnosis (Time 1) (M = 66 days, SD = 45 days) and completed a research survey.

There was a second round of data collection at 9-12 months post-diagnosis (Time 2) (M = 362 days, SD = 45 days) (a copy of the second round research survey is shown in Appendix XIII). A total of 14 patients were excluded from the research study at the second round of data collection. Eight patients were withdrawn from the study by themselves or by the research nurses, either because they were too ill to participate or because they did not wish to take part

again. A further six patients had died since the initial assessment. All other patients (N = 338) were followed up, of whom 279/338 (82.5%) completed the second research survey. Longitudinal data were analysed in this report.

Measures

Socio-economic status

There were four markers of socio-economic status: individual SES (3 categories), Townsend Index (3 categories), income (5 categories) and subjective SES (6 categories), described in detail in Chapter 8.

Psychosocial wellbeing

Psychosocial wellbeing was assessed using a number of questionnaire scales also described in Chapter 8: quality of life, social difficulties, anxiety, depression, benefit finding, and medical interactions.

Analyses

The associations between psychosocial wellbeing and SES at Time 2 were analysed using ANOVAs with SES as the independent variable, and age, gender and cancer sites as control variables. Psychosocial wellbeing: quality of life, social difficulties, anxiety, depression, benefit finding, and medical interactions were the dependent variables. The analyses were carried out using four different SES markers (individual SES [car/home/education], Townsend score, income and subjective SES). Changes in psychosocial wellbeing, and

change in wellbeing in relation to level of SES, were assessed using repeated measures analyses.

An analysis was made of the missing data in both the baseline and the 12-month follow-up data. In cases where the missing data were related to SES or the proportion of missing data was greater than 5% (the depression and social difficulties variables only), the analyses were re-run using imputed values based on the subject mean for each scale if at least half of the items had been completed, and any changes in the outcomes were noted.

Intracluster correlation coefficients for the effect of hospital sites were calculated for all of the dependent variables. Most of the dependent variables had small intracluster correlations (range: 0.001-0.05) (Hox 2002). Again, the social difficulties variable had a large correlation at the second round of data collection (0.16) as well as at the first (discussed in Chapter 8) and any analyses involving this variable included adjustment for clustering due to hospital site.

Results

279 of a possible 338 patients completed the second survey, representing a response rate of 82.5%. There were no differences between responders and non-responders in terms of age, gender, cancer site or disease stage. There was an association between SES and response to the second round questionnaire. The lowest SES groups (using the individual SES marker) were more likely to be non-responders than those in the highest SES groups (27.4% vs 12.1% non-responders) ($\chi^2 = 8.25$, $df = 1$, $p<0.01$).

Table 1 shows the associations between individual SES and psychosocial wellbeing at Time 2. There were no significant associations between individual SES and wellbeing at Time 2. Using a social difficulties variable that included imputed missing data resulted in a significant association between difficulties and individual SES (F [7,214] = 13.03 p<0.01). The 'medium' SES group experienced higher difficulties compared to the other two groups.

The results of the analyses using the other three SES markers are shown in Table 2. Higher income related to decreased benefit finding (F [1,244 = 2.19, p<0.05). Higher subjective SES was related to increase social/family (F [1,234] = 1.56, p<0.05), emotional (F [1,235] = 2.33, p<0.05), functional (F [1,235] = 2.59, p<0.05) and overall quality-of-life (F [1,234] = 2.27, p<0.01). Additionally, there was a trend for higher subjective SES groups to report decreased anxiety (F [1,229] =2.02, p=0.056). The partial eta squared statistic indicated that these were all small effects.

Overall change in psychosocial wellbeing from Time 1 to Time 2 was assessed with repeated measures ANOVAs and the results are shown in Table 3. There were significant changes in emotional quality-of-life (F [1,253] = 4.45, p<0.05), and benefit finding (F [1,239] = 6.36, p<0.01). Again, the partial eta squared statistic indicated small effects. The means in Table 3 show that emotional quality-of-life and benefit finding increased from Time 1 to Time 2, and social difficulties decreased. Table 4 shows the mean change over time for

Table 1 Psychosocial wellbeing by individual SES at Time 2 (9-12 months post-diagnosis), controlling for age, gender and cancer site.

		SES Mean (95% CI)			P	Partial eta²
Psychosocial wellbeing		Low N = 45	Medium N = 101	High N = 124		
Quality of life	Physical	24.00 (22.47-25.53)	23.70 (22.54-24.85)	24.12 (23.15-25.09)	0.889	0.003
	Social/family	20.46 (18.48-22.45)	21.81 (20.39-23.24)	21.92 (20.72-23.13)	0.214	0.006
	Emotional	20.38 (18.89-21.88)	19.18 (18.06–20.31)	19.62 (18.67-20.57)	0.396	0.005
	Functional	21.58 (19.61-23.56)	19.60 (18.15-21.04)	21.42 (20.20-22.63)	0.883	0.018
	Total	86.34 (80.97-91.74)	84.27 (80.41-88.14)	87.07 (83.81-90.33)	0.823	0.008
Social difficulties		4.72 (2.10-7.34)	6.32 (5.06-7.59)	4.59 (3.26-5.91)	0.109	0.011
Anxiety		3.88 (2.35-5.40)	5.16 (4.08-6.25)	4.59 (3.66-5.53)	0.638	0.006
Depression		5.29 (3.27-7.31)	6.23 (4.78-7.68)	5.57 (4.41-6.73)	0.810	0.003
Benefit finding		36.49 (32.10-40.89)	32.80 (29.57-36.02)	36.26 (33.48-39.04)	0.929	0.009
Medical interactions		0.44 (0.22-0.66)	0.37 (0.22-0.52)	0.37 (0.24-0.500	0.594	0.003

Table 2 Psychosocial wellbeing by four different SES markers at Time 2 (9-12 months post-diagnosis), controlling for age, gender and cancer site.

		SES markers							
		Individual		Townsend		Income		Subjective SES	
Psychosocial wellbeing		P	Partial eta²	P	Partial eta²	P	Partial eta²	P	Partial eta²
Quality of life	Physical	0.889	0.003	0.612	0.003	0.331	0.010	0.361	0.021
	Social/family	0.214	0.006	0.778	0.003	0.099	0.028	0.043	0.037
	Emotional	0.396	0.005	0.479	0.004	0.610	0.011	0.046	0.053
	Functional	0.883	0.018	0.769	0.001	0.139	0.025	0.023	0.058
	Total	0.823	0.008	0.513	0.003	0.938	0.007	0.014	0.051
Social difficulties		0.109	0.011	0.764	0.008	0.604	0.020	0.458	0.058
Anxiety		0.638	0.006	0.936	0.001	0.525	0.041	0.056	0.047
Depression		0.810	0.003	0.105	0.011	0.257	0.016	0.141	0.043
Benefit finding		0.929	0.009	0.809	0.003	0.045	0.038	0.836	0.019
Medical interactions		0.594	0.003	0.369	0.005	0.930	0.016	0.040	0.070

levels of the individual SES marker. The increases in emotional quality-of-life and decreases in social difficulties did not significantly differ across levels of SES. Although there appeared to be some differences in the change of benefit finding according to level of SES, in that the 'low' and 'medium' SES group experienced a reduction in benefit finding and the 'high' SES group had a mean increase in benefit finding, this was not a significant interaction (see Table 5).

Analyses using the other SES markers yielded two significant time by SES interactions. The change in anxiety from Time 1 to Time 2 differed by level of income (F [4,222] = 2.86, p<0.05) and the change in satisfaction with medical interactions differed by level of subjective SES (F [5,196] = 2.50, p<0.05). These interactions are shown in Figures 1 and 2. The interactions were difficult to interpret. The highest income group appeared to experience some increase in anxiety from Time 1 to Time 2 whereas all other income groups showed no change or some reduction in anxiety. The interaction in Figure 2 did not have a discernible pattern according to level of subjective SES.

Table 3 Overall change in psychosocial wellbeing from Time 1 (1-3 months post-diagnosis) to Time 2 (9-12 months post-diagnosis), controlling for age, gender and cancer site.

		Time					
		Time 1		Time 2		P	Partial eta²
Quality of life	Physical	22.81	(22.10-23.53)	24.03	(23.31-24.74)	0.080	0.012
	Social/Family	22.24	(21.33-23.16)	21.63	(20.71-22.55)	0.567	0.001
	Emotional	18.02	(17.31-18.73)	19.72	(19.00-20.43)	0.036	0.017
	Functional	18.46	(17.40-19.51)	20.94	(20.02-21.87)	0.073	0.013
	Total	81.77	(79.34-84.19)	86.18	(83.67-88.68)	0.084	0.012
Social difficulties		8.79	(2.67–14.92)	6.47	(3.27-9.67)	0.077	0.021
Anxiety		5.21	(4.45-5.96)	4.59	(3.88-5.31)	0.181	0.007
Depression		5.96	(5.03-6.92)	5.61	(4.62-6.59)	0.863	0.001
Benefit finding		34.99	(32.77-37.23)	35.25	(33.07-37.43)	0.012	0.026
Medical interactions		0.36	(0.26-0.46)	0.40	(0.29-0.50)	0.718	0.001

Table 4 Mean change in psychosocial wellbeing from time 1 (1-3 months post-diagnosis) to time 2 (9-12 months post-diagnosis) by level of individual SES, controlling for age, gender, and cancer site

		SES Mean change (95% CI)					
		Low		Medium		High	
Quality of life	Physical	1.27	(-0.34 - 2.88)	1.60	(0.40 - 2.80)	0.77	(-0.26 - 1.81)
	Social/Family	-1.14	(-3.16 - 0.88)	0.14	(-1.27 - 1.56)	-0.84	(-2.04 - 0.36)
	Emotional	1.68	(0.22-3.14)	2.03	(0.94 - 3.13)	1.39	(0.45 - 2.32)
	Functional	2.57	(0.30 - 4.84)	2.41	(0.80 - 4.03)	2.48	(1.10 - 3.85)
	Total	3.30	(-1.90 - 8.49)	6.27	(2.64 - 9.90)	3.66	(0.56 - 6.76)
Social difficulties		-1.29	(-3.96 - 1.38)	-2.89	(-5.09 - -0.70)	-2.90	(-4.59 - -1.21)
Anxiety		-1.12	(-2.55 - 0.32)	-0.60	(-1.61 - 0.41)	-0.13	(-1.00 - 0.73)
Depression		-0.99	(-3.17 - 1.18)	-0.80	(-2.30 - 0.70)	0.69	(-0.57 - 1.95)
Benefit finding		-1.03	(-4.70 - 2.64)	-0.04	(-2.57 - 2.49)	1.83	(-0.38 - 4.04)
Medical interactions		0.08	(-0.11 - 0.27)	0.03	(-0.11 - 0.15)	-0.01	(-0.12 - 0.11)

Table 5 Change in psychosocial wellbeing by four different SES markers controlling for age, gender, and cancer site

		SES markers							
		Time x individual		Time x Townsend		Time x Income		Time x subjective	
		P	Partial eta²	P	Partial eta²	P	Partial eta²	P	Partial eta²
Quality of life	Physical	0.707	0.003	0.859	0.001	0.770	0.008	0.652	0.016
	Social/family	0.374	0.008	0.649	0.003	0.289	0.022	0.591	0.018
	Emotional	0.762	0.002	0.548	0.005	0.757	0.008	0.409	0.024
	Functional	0.999	0.000	0.332	0.009	0.268	0.023	0.354	0.026
	Total	0.459	0.006	0.473	0.006	0.648	0.011	0.977	0.004
Social difficulties		0.536	0.006	0.598	0.008	0.205	0.006	0.132	0.019
Anxiety		0.367	0.008	0.409	0.007	0.024	0.049	0.947	0.006
Depression		0.692	0.003	0.778	0.002	0.134	0.035	0.719	0.016
Benefit finding		0.355	0.009	0.665	0.003	0.423	0.018	0.480	0.023
Medical interactions		0.692	0.003	0.096	0.019	0.070	0.039	0.032	0.060

Figure 1 - Change in Anxiety by Income

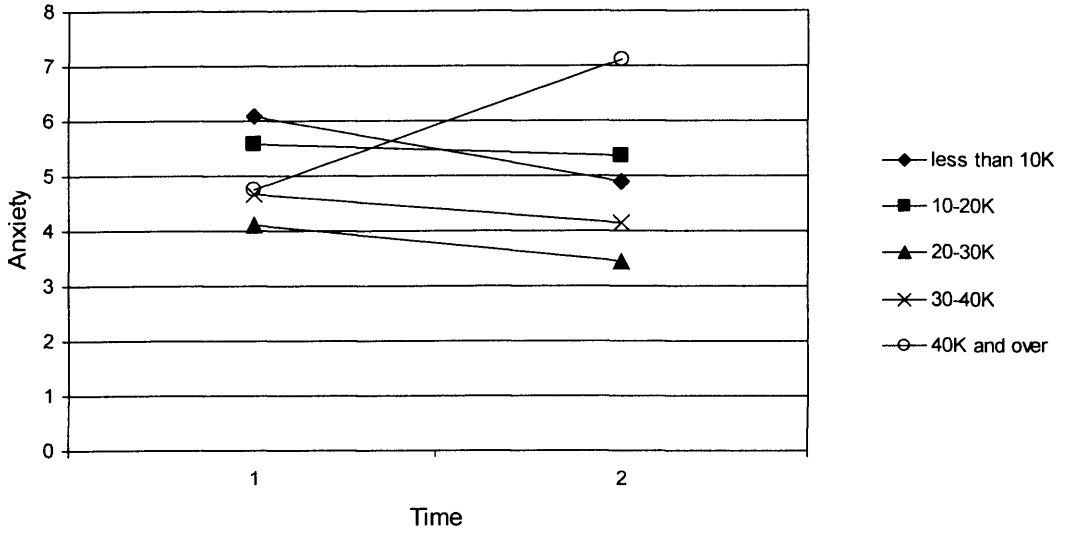
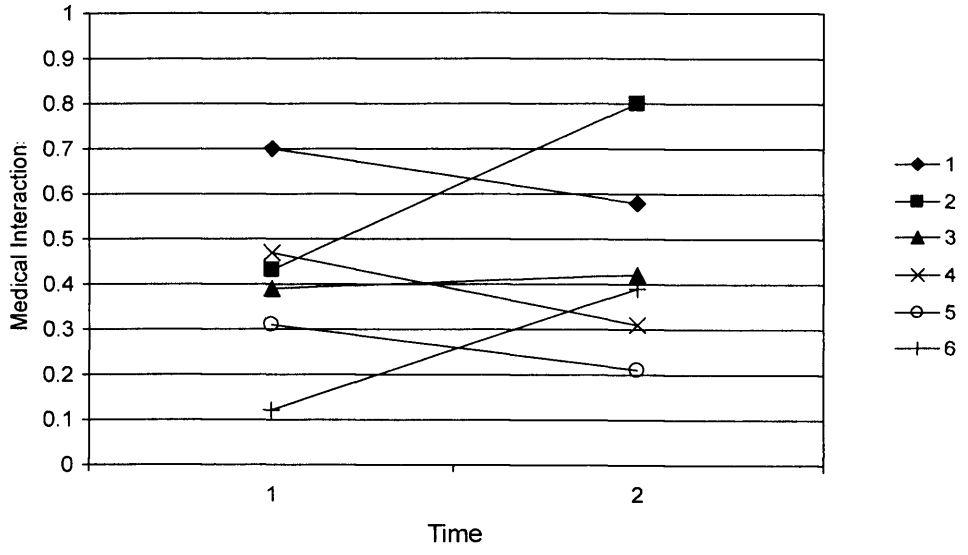


Figure 2 - Change in Medical Interactions by Subjective SES



Discussion

This study explored relationships between SES and psychosocial adjustment to a cancer diagnosis. I hypothesised that lower SES groups would experience poorer psychosocial wellbeing 9-12 months after receiving a cancer diagnosis compared to higher SES groups. I expected that all cancer patients would experience an increase in psychosocial wellbeing over the course of the year from when they first received their diagnosis (i.e. from Time 1: 1-3 months post-diagnosis to Time 2: 9-12 months post-diagnosis), but that this improvement would differ according to SES. I proposed that lower SES groups would experience less improvement in psychosocial wellbeing than higher SES groups.

Study 4 had found an association between subjective SES and quality of life and anxiety in cancer patients who were 1-3 months post-diagnosis. Similar associations were found in the cancer patients 9-12 months post-diagnosis. The relationship between subjective SES and medical interactions that was seen 1-3 months post-diagnosis was not replicated at the 9-12 month assessment. Associations between the marker of individual SES and depression and social difficulties found 1-3 months post-diagnosis were also not found at the 9-12 month assessment. Overall it appeared that SES did not emerge as an important predictor of psychosocial wellbeing in cancer patients who were 9-12 months post-diagnosis. This was surprising given the relationship seen between SES and psychosocial wellbeing in general population studies (e.g. Adler et al 1999, Lorant et al 2003, Power et al 2002). These findings also differed from those in Study 2 where associations between individual SES and anxiety, depression, social difficulties, medical interactions and quality of life were seen.

There were some improvements in psychosocial wellbeing over time: emotional quality-of-life and benefit finding increased. However, other studies have also reported decreases in levels of anxiety and depression (e.g. Burgess et al 2005, Nordin et al 2001, Stommel et al 2004) over the year after diagnosis that were not found in this sample. The lack of association between SES and psychosocial wellbeing and the fact that there were overall few significant changes in psychosocial wellbeing over time suggests that there may be a problem with the sample. One possibility is that the initial sample did not contain patients who were experiencing high levels of distress, either because patients experiencing distress did not want to take part or because the nurses responsible for recruitment to the study did not approach patients who were highly distressed. Comparing the mean score of the HADS-Anxiety scale in the present sample to data from another similar published sample does not seem to support this idea. Nordin et al (2001) studied levels of anxiety using the HADS-A in 522 breast, prostate, colorectal and gastric patients at the time of their diagnosis and six months later. The mean anxiety score in their sample at baseline was 5.3 and 3.6 six months later. This constituted a significant reduction in anxiety. The mean anxiety score at baseline in the present sample was 5.2 and 4.6 12 months later. Although the scores were similar at baseline, the cancer patients in the present sample did not experience a significant overall reduction in anxiety as seen in Nordin et al's sample. If anything, the present sample experience continuously higher levels of anxiety, although it is not clear why this should be the case.

Any changes in psychosocial wellbeing over time did not differ by level of SES. The significant interactions between time and income on anxiety and

between time and subjective SES on satisfaction with medical interactions were ambiguous and did not amount to clear evidence of SES differences in adjustment. The longitudinal results from Study 1 examining psychological adjustment to bowel cancer screening (pre to post-screening) also did not find any evidence of differential adjustment by level of SES. Taken together, these results imply that SES does not affect psychosocial adjustment over time to novel stressors.

A limitation of this study is that there was a bias in response to the second round questionnaire by level of SES. Lower SES patients were less likely to complete the second round questionnaire. This may have introduced bias into the longitudinal results if the lower SES patients who did not complete the second round questionnaire differed in some way from those that did, although it is obviously not possible to check for this type of bias. Other limitations of the study design included the recruitment strategy and problems with power previously discussed in Chapter 8.

The results from this study suggested that the effect of a cancer diagnosis could serve to diminish rather than enhance SES differences in psychosocial wellbeing. The threat and stress of the diagnosis may serve to worsen the wellbeing of high SES groups so that the levels of wellbeing they experience become comparable to that of the lower SES groups – resulting in there being little or no SES differences in wellbeing. These findings must be treated tentatively, especially in the light of somewhat contradictory evidence seen in Study 2. Sampling issues resulting in bias could have skewed the results. The differences between the two samples are discussed in more detail in the following chapter.

CHAPTER 11

Discussion

The aim of the present series of studies was to explore how people from different socio-economic backgrounds react to novel stressors in terms of their psychosocial wellbeing. A review of the literature suggested that people from lower socio-economic groups could be more vulnerable to adverse psychosocial outcomes in the face of new stressors, but there was still a scarcity of research in this area. The strategy used to examine this issue was to explore psychosocial reactions to a range of new, 'real life', stressful situations, ranging from less to more severe experiences. Cancer-related stressors provided a framework within which to research this topic. Specific characteristics of each stressful situation were looked at in terms of their interactions with SES and adjustments to stressors over time by level of SES were also investigated.

Summary of main findings

A summary of the main findings from each research study is provided in Table 1. Firstly, a moderate stressor, that of bowel cancer screening was examined. There were three different screening outcomes (negative, polyps detected, additional colonoscopy required) that posed progressively greater threats. SES differences in reactions to these screening outcomes were explored as well SES differences in adjustment (pre-post screening) to the screening

Table 1 Summary of main findings

	Stressor	Sample	Psychosocial Outcomes	SES indicators	Results	Conclusion
Study 1	Bowel cancer screening: Adjustment over time Different screening outcomes	Longitudinal pre to post screening (N = 3535) Cross-sectional post-screening (N =29,804)	Anxiety Bowel cancer worry Distress Positive consequences of screening	Individual SES Townsend	Anxiety and worry higher in lower SES groups. Lower SES report more positive consequences of screening. Anxiety and worry reduce pre-post screening. More pathology (polyps/colonoscopy) associated with lower anxiety and worry post-screening. Change over time not different by SES. No differential effect of SES depending on screening outcome	Differences in psychological well-being by SES typical of the general population. No interaction between SES and time or level of stressor (screening outcome). Lower SES groups not more vulnerable to effects of the stressor.

	Stressor	Sample	Psychosocial Outcomes	SES indicators	Results	Conclusion
Study 2	Bowel cancer diagnosis Stage of disease	Cross-sectional (N = 128)	Quality of Life Depression Anxiety Social Difficulties Medical Interactions Social Support	Individual SES	Lower SES associated with worse psychosocial outcomes (quality of life, anxiety, depression, medical interactions, social difficulties and social support) Advanced disease stage associated with worse psychosocial outcomes (quality of life, anxiety, depression, social difficulties, social support) SES interacts with disease stage for anxiety and social support. High SES have lower anxiety across all disease stages, lower SES show increases in anxiety across disease stage. Low SES had less social support with advancing disease stage than high SES.	Differences in wellbeing by level of SES typical of the general population. Level of stressor (disease stage) affected wellbeing. Some evidence lower SES moderated reactions to the diagnosis.
Study 3	Bowel cancer diagnosis	Qualitative (N = 24)	Satisfaction with medical interactions	Education	Patients most often discussed their interpersonal relationships with care providers. Most negative comments related to organisational aspects of the service. Specialist nurses received the most positive comments. Low SES less likely to comment about their experience of specialist oncology services, either positively or negatively	Little evidence that the experience of care differed by SES. Lower SES may be less likely to evaluate or be critical of care. If there are differences in the way care providers interact with low SES patients they do not translate into dissatisfaction.

	Stressor	Sample	Psychosocial Outcomes	SES indicators	Results	Conclusion
Study 4	Mixed-cancer patients (bowel, breast, prostate) Stage of disease Treatment type Co-morbidity	Cross-sectional (N = 352)	Quality of Life Anxiety Depression Social difficulties Medical interactions Benefit finding	Individual SES Townsend Income Subjective SES	Lower individual SES associated with worse social difficulties, depression and family quality-of-life. Lower subjective SES associated with worse quality of life, anxiety and dissatisfaction with medical interactions. Advanced disease associated with worse quality of life, increased anxiety, depression, social difficulties. Having chemotherapy associated with worse functional quality-of-life, more social difficulties and dissatisfaction with medical interactions. Co-morbidity associated with worse quality of life. High SES patients with advanced disease have better family quality of life than low SES patients with advanced disease. There are SES differences in quality of life in those who do not have surgery or who do not have hormone therapy, but these differences disappear once patients receive the treatment.	Not as consistent findings of general population differences in wellbeing by SES as that seen in Study 2. Level of stressor (disease stage) affects psychosocial wellbeing. Inconsistent effects of treatment and co-morbidity on wellbeing. Some interactions between stressors and SES on psychosocial wellbeing. Unlike Study 2, effect of having treatment diminished SES differences in wellbeing rather than increased them. Interactions between SES and disease stage on anxiety not replicated. There was an interaction between family quality-of-life that differed from the 'treatment' interactions in that the SES difference in wellbeing widened rather than diminished. Raises the possibility that differences in wellbeing by SES are levelled out or diminished (not increased) by the stress of receiving a cancer diagnosis and treatment for it.

	Stressor	Sample	Psychosocial Outcomes	SES indicators	Results	Conclusion
Study 5	Mixed-cancer patients (bowel, breast, prostate)	Cross-sectional (N = 352)	Personal control Optimism Social support Coping Strategies	Individual SES Townsend Income Subjective SES	Higher SES had more personal control and optimism. Increase control and optimism were related to better psychosocial wellbeing. SES and resources predicted wellbeing in a regression model, but the variance explained was relatively low.	Psychosocial resources are related to SES. Psychosocial resources are related to wellbeing. Weak associations between SES and psychosocial wellbeing in Study 5 precluded a mediational analysis of the effects of psychosocial resources explaining SES differences in wellbeing.
Study 6	Mixed-cancer patients (bowel, breast, prostate) Adjustment over time	Longitudinal (N = 278)	Quality of Life Anxiety Depression Social difficulties Medical interactions Benefit finding	Individual SES Townsend Income Subjective SES	No SES differences in psychosocial wellbeing 9-12 months diagnosis using individual SES. Subjective SES differences in wellbeing 9-12 months diagnosis for quality of life. Some improvements in psychosocial wellbeing over time, for emotional quality-of-life, benefit-finding. Interaction analyses did not yield any interpretable patterns of differences in adjustment by SES.	Fewer SES differences in wellbeing 9-12 months post-diagnosis than at 1-3 months post-diagnosis (Study 4). Lends further support to the idea that differences in wellbeing by SES may be diminished rather than increased by the stress of being diagnosed with cancer.

process. Although lower SES groups experienced higher anxiety and worry about bowel cancer overall, SES did not moderate psychological adjustment over time. This study provided no support for the hypothesis that lower SES groups would be more vulnerable to adverse psychosocial outcomes in the face of a novel stressor.

The subsequent research studies in the thesis concentrated on the more severe stress of receiving a cancer diagnosis. Although this thesis is primarily concerned with SES and psychosocial outcomes and does not focus on the processes by which SES and outcomes are linked, Study 5 did make a preliminary exploration into this area. A mediational analysis of the effects of psychosocial resources in explaining SES differences in wellbeing was not possible because there were only weak associations between SES and psychosocial wellbeing (Baron & Kenny 1986). However, the hierarchical regression analyses did investigate the combined contribution of SES and resources on psychosocial wellbeing, but the results indicated that the proportion of variance explained was relatively low. Other unmeasured factors must have a part to play in predicting wellbeing and could include: personality traits (de Jonge et al 2004, Penninx et al 1998), past history of mental illness (Burgess et al 2005) and other physical symptoms or side-effects, such as cancer-related fatigue (Barsevick et al 2006).

Interactions between SES and characteristics of the cancer experience on psychosocial wellbeing were examined in Studies 2, 4 and 6. Reactions to more or less advanced disease stage diagnoses, undergoing different types of cancer treatments, and the effect of having a co-morbid illness were investigated.

Study 2 found some evidence greater vulnerability for lower SES groups in the face of a cancer diagnosis. Higher SES groups maintained lower levels of

anxiety regardless of disease stage, whereas lower SES groups experienced increasing anxiety with increasing disease stage. However, this effect was not replicated in Study 4. The findings from Study 4 suggested that SES differences in wellbeing may be diminished by the effects of undergoing treatment for cancer. Specifically it appeared that there were small SES differences in wellbeing amongst those that did not receive surgery, but that these differences disappeared amongst those who did receive surgery. The findings from Study 6 lent further support to the idea that experiencing a cancer diagnosis could reduce SES differences in wellbeing rather than increase them. There was little evidence of any SES differences in wellbeing at the 9-12 month post-diagnosis assessment. This is contrary to findings from general population studies which consistently report that SES differences in psychological wellbeing (Lorant et al 2003, Power et al 2002). The findings from Study 6 thus imply that experiencing cancer can diminish these SES differences.

The differences in the findings from Study 2 (colorectal sample) versus Studies 4 and 6 (mixed sample) could have a variety of explanations. One possibility is that there were fundamental differences between the two samples in terms of psychosocial wellbeing – one or other sample may not have been representative because of the different sampling frames and recruitment strategies resulting in one sample containing patients that were more or less distressed. This could in turn have had an impact on analyses of SES differences. The mean scores for each psychosocial outcome for the different samples are shown in Table 2. There were a few significant differences between the scores in the Study 2 sample compared to the sample in Studies 4-6. The Study 2 sample were

slightly less anxious (F (1,462) = 7.09, p<0.01) and had better emotional quality-of-life (F [1,467] = 1.42, p<0.05) than the baseline assessment of the longitudinal study. But the Study 2 sample had slightly worse functional quality-of-life (F [1,398] = 6.82, p<0.01) and more social difficulties (F [1,362] = 5.23, p<0.05) than the follow-up (Time 2) assessment in the sample used in Studies 4-6.

The overall picture suggested that psychosocial wellbeing may be affected by time since diagnosis. The Time 1 assessment of the longitudinal sample had the worst psychosocial wellbeing (Mean = 66 days post-diagnosis), the Study 2 sample (Mean = 257 days post-diagnosis) had slightly better wellbeing, and the Time 2 assessment of the longitudinal sample (Mean = 362 days post-diagnosis) had the best psychosocial wellbeing. However, any difference in wellbeing depending on time since diagnosis does not seem to be a plausible explanation of the differences in results between the samples as Study 2's timing is between the first and second assessment of the longitudinal sample.

Given that fundamental differences between the two samples were small, this may not be an explanation of the different results and another explanation must be sought. The results may not necessarily be as inconsistent as they first appear. As regards the interaction effects, the effect of prognostic factors such as disease stage, compared to the effect of treatments for cancer in relation to SES may be different. Being diagnosed and treated for cancer may serve to diminish SES differences in psychosocial wellbeing, but this effect could be reversed in the face of a palliative diagnosis.

Table 2 Comparison of mean psychosocial wellbeing scores across samples

		Sample - Mean (SD)		
		Studies 4-6 – Time 1 N = 352	Study 2 N = 128	Studies 4-6 – Time 2 N = 279
Average time since diagnosis		66 days	257 days	362 days
Quality of Life	Physical	22.48 (4.55)	23.28 (5.07)	23.65 (4.37)
	Emotional	17.92 (4.50)	19.06 (4.83)	19.30 (4.36)
	Functional	18.37 (6.24)	19.20 (6.71)	20.86 (5.45)
	Social/Family	22.25 (5.40)	21.57 (5.46)	21.93 (5.31)
	Total	81.07 (14.64)	83.09 (16.34)	85.68 (14.52)
Depression		6.38 (5.27)	6.14 (5.47)	5.85 (5.06)
Anxiety		5.53 (4.50)	4.28 (4.24)	4.96 (4.17)
Social difficulties		7.67 (7.21)	8.72 (8.58)	5.82 (7.31)
Medical interactions		0.40 (0.74)	0.39 (0.64)	0.40 (0.58)

That there were fewer main effect SES differences in psychosocial wellbeing in the longitudinal sample compared to the Study 2 sample is not due to the socio-economic distributions of the samples. There were no differences between the two samples in terms of their socio-economic distribution (individual SES marker: $\chi^2 = 2.01$, $df = 1$, NS, townsend thirds: $\chi^2 = 0.01$, $df = 1$, NS). One possibility is that the findings in Study 2 were affected by the hospital setting. Study 2 was a single site study and procedures or medical interactions particular to that hospital could have affected the results.

Although the different studies reported some interaction between severity of stressor and SES, overall there was not compelling evidence that SES moderates psychosocial wellbeing in response to novel stressors. However, the research studies did have other important findings that related to the particular situations

that were investigated. Study 1 examined psychological reactions to a bowel screening test and importantly found that anxiety was reduced after screening, rather than increased. Also people who received additional tests experienced the greatest reductions in anxiety. This is an important finding within the literature on screening tests for cancer where there is a concern that screening for cancer will increase anxiety and worry (Wardle & Pope 1992).

Studies 2 and 4 showed a consistent relationship between disease stage and psychosocial wellbeing. This has been an area of research fraught with a number of difficulties and inconsistent findings. Some studies show that more advanced disease is associated with poorer psychological well-being (Gallagher et al 2002, e.g. Osborne et al 2003, Shimozuma et al 1999) whilst others studies find little or no relationship (Bleiker et al 2000, Kissane et al 2004, Norum 1997). One problem is that studies do not always include patients in the most advanced disease stage (e.g. Bleiker et al 2000). Another difficulty is when comparisons between early and advanced stage patients are made in widely different time frames since diagnosis (e.g. Kissane et al 2004). Study 2 included a proportion of patients with advanced disease and those who were receiving palliative care. Study 4 used a tight frame of time since diagnosis. Both studies found an association between increasing disease stage and poorer psychosocial wellbeing and consequently make a useful contribution to this research area.

Finally, Study 5 explored the relationships between a number of psychosocial resources and SES. The relationship between SES and optimism in particular has not been researched in any great detail previously. The research study in this thesis together with data I have analysed and submitted for

publication from the Flexible-Sigmoidoscopy trial (discussed in Chapter 1, see Appendix I) show that lower SES is associated with decreased optimism. This may be important in so far as optimism is implicated in psychosocial adjustment and physical wellbeing (Schou et al 2004, Segerstrom 2005).

Limitations

Use of different SES markers

There were many limitations to the research describe in this thesis. Most serious was that I could not come to a conclusion about the most appropriate SES indicator, which resulted in multiple testing. No one marker seemed more or less appropriate and the measurement of SES was more uncertain than I had initially expected.

The most effective SES indicators (in terms of detecting any differences in wellbeing) in the samples used in this thesis appeared to be the composite, individual SES score and the subjective SES scale. The composite score was useful in Study 2 and to a lesser extent in Studies 4-6. This method was based on a recommendation from another study examining the effectiveness of SES indicators in older adults (Grundy & Holt 2001).

The use of subjective SES as indicator in older age samples had not been considered in any detail and the subjective SES marker used in this thesis is relatively new (Adler et al 2000). One study that looked at cortisol response to awakening (CAR) in older adults (age 65-80 years) in relation to SES found that subjective SES was more robustly related to CAR than objective measures of

education or financial strain (Wright & Steptoe 2005). This finding also suggests that subjective social status could be a useful marker in older populations.

The Townsend Index was also useful in the analyses of the Flexible-Sigmoidoscopy dataset in Study 1, but appeared to lose its sensitivity in the subsequent samples. This was probably due to the fact that the Index was based on 1991 census data. The sample in Study 1 had a data collection period starting in 1994, whereas the subsequent studies collected data from 2002 onwards. The accuracy of the Index was probably better for the earlier periods of data collection.

This topic clearly needs further research which specifically focuses on the measurement of SES in elderly populations. This was not within the remit of the current thesis and no definite conclusions could be reached.

Use of multiple psychosocial outcomes

A related issue was the use of multiple psychosocial outcomes, which could have increased the probability of Type I error (i.e. finding a significant result that does not really exist). The cancer literature often uses this strategy because many areas of life are affected by receiving a diagnosis. It is really not appropriate to use single measures of wellbeing e.g. just assessing depression whilst ignoring the impact of cancer on other areas of life. I did not adjust p-values to compensate for this problem because this can have the effect of increasing Type II errors (i.e. finding a non-significant result when an effect really does exist) and this also has implications for power and sample size. Larger sample sizes would have been needed in order to adjust the p-value and still provide meaningful results. Consequently, I took the approach of looking for consistent findings across a

number of psychosocial outcomes and samples and tried not to read too much into a single significant result.

Samples

Power

Study 1 had large sample sizes and sufficient power to detect small effects. However, the subsequent studies in cancer patients all suffered from low power and consequently affected the conclusions that could be drawn from the analyses. Any analyses looking at interactions between SES and stressor on wellbeing were compromised by this as small effects may have remained undetected. This means that larger studies will be needed in order to confirm or disprove the findings of this thesis.

However, the sample sizes used in this thesis were often as large as or larger than other studies that examine wellbeing in cancer patients. Recruiting a clinical sample, such as cancer patients, is often difficult and time consuming. Generally SES effects have been explored in terms of public health in larger, epidemiological settings rather than within smaller, clinical studies. It is possible that effects of SES in terms of population health may be more important than the smaller effects of SES found in this thesis' smaller, clinical samples.

Bias

The response rates for the research studies in this thesis were variable. The post-FS sample in Study 1 had a response rate of 90.7%. The samples for the other studies had response rates between 60.4% and 67%. A review of response rates published in medical journals reports that the average response

rate is about 60% (Asch et al 1997). Response rates are usually taken to be an indication of how representative the sample is of the population. A low response rate is only a problem if it is likely to have introduced bias. Bias in response by SES is common in other research survey studies (Sheikh & Mattingly 1981, e.g. Turrell et al 2003). Where possible I analysed SES differences in response rates.

In Study 2 there was no evidence of SES response bias in returning the research questionnaire. In Study 1 there was some evidence that non-response was related to lower SES, as measured by the Townsend Index. However this sample had an extremely high response rate and this effect was likely to be small (partial eta squared = 0.004). In Study 6, lower SES groups were also less likely to respond to the second round of data collection, based on a comparison with the baseline sample. Unfortunately, the recruitment strategy of the longitudinal sample in Studies 4-6 (where research nurses approached patients) meant that I was unable to collect information about SES bias comparing baseline responders to non-responders. Using a weighting to correct for SES bias found in a comparison with a baseline sample maybe inappropriate if the baseline sample itself is non-representative and so I did not use this route to correct for bias. The bias by SES limits the generalisability of the research findings and questions the reliability of the findings in relation to SES and adjustment to stressors.

Design

The research studies in this thesis used a variety of research designs: longitudinal and cross-sectional, multi-centre and single centre, quantitative and qualitative, mixed-cancer sites and single cancer sites. There are different

strengths and weaknesses associated with the different strategies. For example, the design of Study 2 used a single cancer site (bowel cancer) within a single hospital site and used cross-sectional data. The use of a single type of cancer at one hospital meant the results were easier to interpret but limited the generalisability of the research. The design in Studies 4-6 used mixed-cancer sites at multiple hospital centres and had longitudinal data collection. This possibly makes the results more generalisable but produces difficulties in the analysis and interpretation of the data e.g. taking account of clustering and differences in psychosocial wellbeing according to different types of cancer site. The multi-centre, longitudinal design also necessitated a change in recruitment strategy so that not all new cancer patients within each hospital were reached, whereas the single centre design and recruitment strategy in Study 2 meant that all new cancer patients in a one-year period were approached. Using these different strategies may have caused some of the differences in results between the two datasets.

Lack of control sample

The research studies in this thesis did not make use of a healthy control sample. This could have been useful for showing that cancer patients were experiencing greater levels of stress and for proving differential reactions to stress in relation to SES compared to healthy subjects. I did not choose to recruit a control sample for a number of reasons:

- It was not clear what would constitute an appropriate control sample in terms of their demographic characteristics or how to recruit such a sample.

- It is well known, and well researched, that there are SES differences in psychosocial wellbeing amongst the general population and so there was no need to replicate this effect.
- Other studies and reviews have already shown that there are higher levels of distress amongst cancer patients compared to general population samples.
- The psychosocial outcome variables were based on standardised questionnaires and so values in the present sample could easily be compared to those found in other studies.
- The analytic strategy looked at interactions of SES with specific characteristics of the situation and adjustment over time and did not rely on an analysis of main effects. Therefore it was possible to distinguish between what might have been population effects of SES and actual reactions to stressors.

Conclusions and directions for future work

The overall picture of results in this thesis is that a vulnerability effect by SES in response to new stressors is not a striking effect. If a vulnerability effect does exist, it is likely to be small. Of course, the results from the studies need to be replicated to be certain of this. Future research studies that aim to replicate or refute these findings would need to recruit larger sample sizes to achieve adequate power for sub-group and mediational analyses.

The results also raise the interesting possibility that exposure to new stressors reduces the gap in psychosocial wellbeing rather than increases it. Additional research studies that use a longer follow-up period, with assessments

at additional time points, could help to establish whether SES differences re-emerge over time or whether these changes are permanent.

The results could be specific to the cancer-related stressors explored in this thesis. Further work could explore SES differences in reactions to other types of illnesses such as multiple sclerosis or diabetes, and also among people experiencing sudden onset, acute illnesses, such as an unexpected cardiac event. Another issue with this series of studies is that because of the nature of the types of cancer that were studied, the research has been restricted to an older age and retired population. It could be useful to explore SES differences in a younger group as well, for example, those with a recent testicular cancer diagnosis. The finding that experiencing an illness could reduce disparities in wellbeing is contrary to what might be expected. Therefore, this kind of additional research is crucial for exploring the accuracy and generalisability of these results.

This thesis explored the relationships between SES and psychosocial outcomes and did not examine the processes that underlie these connections. Clearly this is another important avenue of research that is needed in order to understand the mechanisms by which SES and wellbeing are linked.

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Appendices

Appendix I: Paper submitted for publication: Socioeconomic disparities in optimism

Submitted to: *Health Psychology*

Kathryn A Robb, Alice E. Simon, Jane Wardle

Abstract

We assessed the relationship between socioeconomic status (SES) and trait optimism to test the hypotheses that i) there would be a socioeconomic gradient in optimism and ii) the SES gradient would be stronger for negative than positive optimism. Community samples of adults (55-64 years) from Scotland (N=10,650) and England (N=5,099) were sent a questionnaire assessing optimism (Life Orientation Test) and SES. In both samples there was a strong SES gradient in optimism. When negatively and positively worded items were analyzed separately, the gradient remained significant in both cases, although the effect was significantly stronger for the negatively worded items. Lower SES is associated with viewing the future as containing fewer positive and more negative events. This bleak view on the future may have important implications for health.

Keywords: Socioeconomic status; SES; dispositional optimism; psychosocial

Introduction

The association between socioeconomic status (SES) and health has been well established for several decades (Adler et al., 1994; Lawlor, Smith, & Ebrahim, 2004; Marmot, Shipley, & Rose, 1984). It has been observed across multiple different causes of morbidity and premature death, and using a variety of different measures of socioeconomic position (Bartley, 2004; Krieger, Chen, Waterman, Rehkopf, & Subramanian, 2005; Marmot, 2004; Mirowsky & Ross, 2003). The effect is not just one of a difference between people living at the poverty level and the more prosperous sectors of society; rather there is a graded relationship with health across the whole spectrum of SES (Adler et al., 1994; Marmot et al., 1984; Marmot et al., 1991).

Social epidemiologists have emphasized the role of psychosocial factors such as perceived control (Griffin, Fuhrer, Stansfeld, & Marmot, 2002; Marmot, Bosma, Hemingway, Brunner, & Stansfeld, 1997) and social affiliations (Mickelson & Kubzansky, 2003; Stansfeld & Marmot, 1992; Turner & Marino, 1994) in mediating the relationship between SES and health, but health psychologists have paid limited attention to the investigation of SES disparities. One potential candidate that could have widespread effects is so-called dispositional optimism: the generalized belief that more good than bad things will happen (Scheier & Carver, 1985). There is a mass of evidence that an optimistic outlook on life is a relatively stable trait that is associated with a wide range of health behaviors and health outcomes (Giltay, Geleijnse, Zitman, Hoekstra, & Schouten, 2004; Ironson et al., 2005; Lobel, DeVincent, Kaminer, & Meyer, 2000; Peterson & Bossio, 2001).

Related traits such as perceptions of control (Rothbaum, Weisz, & Snyder, 1982) have been shown to be related to SES, but there appears only to be one report on SES differences in optimism, and that was only a summary of the association (Taylor & Seeman, 1999). Taylor and Seeman described data on associations between optimism, as measured by the Life Orientation Test (LOT; Scheier & Carver, 1985) and SES in four unpublished datasets. They included individuals having been through a hurricane (n=168); patients recovering from coronary artery bypass surgery (n=234); women at risk for HIV (n=256); and a study of the natural history of HIV in gay men (n=unknown). In all four studies, total optimism scores were positively correlated with SES, but when the positively and negatively worded items were analyzed separately, the negative optimism items were significantly related to SES, while the positive optimism showed no association. These results suggested that lower SES people expect more bad things to happen but not fewer good things, but the empirical data describing the association between SES and optimism has never been published.

The present study assessed the relationship between SES and optimism, also using the LOT, in two large samples of older British adults. We hypothesized that i) total optimism score would be linearly associated with SES, and ii) when analyzed separately, negative but not positive optimism, would show an SES gradient.

Methods

Participants and procedures

Potential participants were all men and women aged 55-64 years, registered with participating Primary Care Practices taking part in the UK Flexible Sigmoidoscopy Trial (Atkin et al., 2001; UK Flexible Sigmoidoscopy Screening Trial Investigators, 2002),

excepting the 2% who were judged by their General Practitioner to be unsuitable for screening (e.g. already had bowel cancer, recently had sigmoidoscopy, very ill). The data come from the baseline assessment in Glasgow, 'the Scottish sample' (N=10,650), and two centers in England, Welwyn Garden City and Leicester, 'the English sample' (N=5,099). Participants were mailed a letter, signed by their GP, informing them that a trial of colorectal cancer screening was being set up in their area and requesting that they complete an enclosed questionnaire and return it in the pre-paid reply envelope. Non-respondents were sent a reminder questionnaire after two weeks. Ethical approval was obtained at local Ethics Committees for each centre.

Measures

The Scottish and English samples received the same questionnaire items on the following measures.

Dispositional optimism. Optimism was assessed using the LOT (Scheier & Carver, 1985). The LOT consists of four positively phrased items (e.g. 'In uncertain times, I usually expect the best') and four negatively phrased items (e.g. 'I hardly ever expect things to go my way'). Response options ranged from 'strongly disagree' to 'strongly agree' on a five-point Likert scale scored from zero to four. Higher scores represent greater optimism. Internal reliability was strong in both the Scottish sample (Cronbach's α=0.79) and the English sample (Cronbach's α=0.81).

Demographic characteristics. Age and gender were known from Health Authority records. Simple items were used to assess ethnicity ('White; Black; Asian; other; do not wish to answer'), marital status ('married/living as married; divorced; separated; widowed; single'), occupational status ('working full-time; working part-time; not working at

present; retired'), car ownership ('no car; one car; two cars'), educational qualifications (passed public examinations within school or college; 'yes; no') and housing tenure ('owning home; renting home'). An individual-level score of socioeconomic deprivation was created by combining answers to questions on educational qualifications, housing tenure and car ownership ranging from zero (high SES) to four (low SES) (Wardle, McCaffery, Nadel, & Atkin, 2004). In the present analysis, the two most deprived groups were combined to ensure sufficient numbers in each group, yielding four SES groups. We opted to assess SES this way rather than with the more conventional markers of occupational status or income because the age group of our sample meant that many were retired or unemployed so did not have a current occupation, while some were working in post-retirement jobs that were different from their previous occupation. Further, half the sample were women, whose SES is poorly indicated by occupation. The individual-level index we employed is similar to the Townsend Material Deprivation Index (Townsend, Phillimore, & Beattie, 1988) or its Scottish equivalent 'Neighborhood Type' (Greater Glasgow Health Board, 1995) which are indices of neighborhood-level socioeconomic deprivation derived from census information on housing tenure, car ownership, unemployment, and overcrowding in the local area. We used the individual-level index for the current analysis for greater precision in view of our use of an individual–level measure of optimism, but the associations between our individual-level marker of SES and the neighborhood-level measures suggested correspondence between the measures (Scottish sample: correlation between individual deprivation and Neighborhood Type score $r=0.47$, $p<.001$; English sample: correlation between individual deprivation and Townsend score $r=0.44$, $p<.001$).

Analysis of results

Results were analyzed using SPSS (Version 13). The Scottish and English samples were analyzed separately because the Scottish sample used a different sampling frame, and over-sampled more socioeconomically deprived areas. Chi square tests and independent-samples t-tests were used to examine differences between respondents and non-respondents. ANOVAs and chi square tests were employed to look at demographic differences across the SES groups. The relationship between SES and dispositional optimism was assessed using linear one-way ANOVAs and Pearson correlations.

Results

The Scottish sample

In the Scottish sample, of the 10,650 people sent a questionnaire, 6,383 (60%) returned a completed questionnaire. More women (62%) than men (58%) responded ($\chi^2(1, N=10,650) = 9.95$, $p<.001$), and respondents were very slightly (mean age 60.2 years) older than non-respondents (mean age=60.0 years; $t(10,648)=3.63$, $p<.001$). Previous analyses of the data from the Scottish centre have shown that response was lower among people living in more deprived neighborhoods (McCaffery, Wardle, Nadel, & Atkin, 2002).

Respondents in the highest SES category were younger ($F(3, 5,869)=11.6$, $p<.001$), more likely to be married ($\chi^2=(3, N=5,857)=312.2$, $p<.001$), and more likely to be in full-time employment ($\chi^2(9, N=5,836)=551.3$, $p<.001$), see Table 1. There were no differences in gender or ethnicity across the SES groups, see Table 1.

The total optimism score showed a significant linear relationship with SES ($r=0.23$, $p<.001$), with higher optimism in the higher SES groups, see Table 2. The pattern of results was the same when men and women were analyzed separately, and there was no

gender by SES interaction. When negative items were considered separately, a strong positive association emerged, with higher SES groups showing a stronger belief that bad things were unlikely to happen ($r=0.31$, $p<.01$). The relationship between positive optimism and SES was also linear, but the association was very much weaker than for the negative items ($r=0.04$, $p<.01$).

The English sample

In the English sample, 3,648 (71.5%) questionnaires were returned of the 5,099 sent out. Women (77%) were more likely to return the questionnaire than men (68%; $\chi^2(1, N=5,099)=392.9$, $p<.001$). Respondents were slightly older (mean age 60.1 years) than non-respondents (mean age 59.8 years; $t(5,047)=2.84$, $p=.005$).

Respondents in the higher SES groups were younger ($F(3, 3,473)=7.60$, $p<.001$), more likely to be male ($\chi^2(3, N=3,474)=37.0$, $p<.001$), white ($\chi^2(3, N=3,429)=14.3$, $p=.003$), married ($\chi^2(3, N=3,436)=327.8$, $p<.001$), and in full-time employment ($\chi^2(9, N=3,379)=159.2$, $p<.001$), see Table 1.

SES was linearly associated with the total optimism score ($r=0.22$, $p<.001$), with higher SES groups reporting greater optimism, see Table 2. Similar effects were seen in men and women when they were analyzed separately. The relationship between negative optimism and SES was also significant and graded ($r=0.29$, $p<.001$). Positive optimism was significantly related to SES ($r=0.04$, $p<.01$), indicating that higher SES groups reported a greater belief that positive things were likely to happen, however the relationship did not show a dose-response pattern, see Table 2.

Discussion

The aim of this study was to examine the relationship between SES and optimism in two community samples of older British adults. As predicted, higher SES people were more optimistic. Unlike previous reports, we found significant SES gradients for both positively and negatively-worded optimism scales, although the size of the association between SES and the positively worded items was very small, and the datasets described by Taylor and Seeman (1999) would have been underpowered to detect such a small effect.

Optimism is a psychosocial resource that could potentially contribute to the relationship between SES and health. It may exert its influence on health through greater engagement and interest in health leading to successful uptake of health behaviors (Ironson et al., 2005; Lobel et al., 2000) or because people with an optimistic disposition would be more likely to believe that the impediments they face can be overcome (Scheier & Carver, 1985). Studies examining the relationship between optimism and health-promoting behaviors have found that more optimistic individuals have better dietary practices, lower alcohol consumption and lower smoking rates (Robbins, Spence, & Clark, 1991; Steptoe et al., 1994).

Optimists also appear to experience less distress during stressful events which provides another explanation of how optimism can have a positive impact on health. Even when confronted with events as severe as a cancer diagnosis, optimists seem to fare better (Carver et al., 1993; Epping-Jordan et al., 1999; Schou, Ekeberg, Ruland, Sandvik, & Karesen, 2004; Stanton & Snider, 1993), perhaps because they tend to use more-problem-focused coping strategies or, when they are not appropriate (e.g. when the situation is uncontrollable), to turn to emotional coping strategies that are effective in the particular situation (Scheier, Weintraub, & Carver, 1986).

Generalization of these results is limited by several factors. Our samples had a limited age range (55-64 years) and so it is possible that the relationship is a cohort effect and would not generalize to other age groups. However, given that the pattern of results is similar to the datasets described by Taylor and Seeman (1999), we think that this is unlikely. Our samples were predominantly white and we cannot assume that the same relationship would be seen in different ethnic groups. The response rate was only 60% in the Scottish sample and only 72% in the English sample. These response rates are typical of primary care surveys (e.g. Walsh, 1994), but it means that we do not know the responses of between 28-40% of potential participants. Response rates to postal questionnaires tend to be lower among more socioeconomically disadvantaged groups (McCaffery et al., 2002) which suggests that our samples may not include the lowest SES groups. However, given the graded relationship we found between SES and optimism, we would hypothesize that the non-responding group would report low levels of optimism.

The study is the first of its kind to present data on the relationship between SES and optimism, and our samples were sufficiently large for us to be confident of the reliability of the association. The results suggest that lower SES people view the future as containing fewer positive and more negative events. This bleaker view on the future may have implications for preventive health behaviors, resilience in the face of stress, or mental health.

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Table 1

Differences in demographic characteristics between the four socioeconomic status groups in the Scottish and English samples

	Scottish sample				English sample			
	SES Group 1 (n=1293)	SES Group 2 (n=1846)	SES Group 3 (n=1891)	SES Group 4 (n=840)	SES Group 1 (n=1326)	SES Group 2 (n=1409)	SES Group 3 (n=523)	SES Group 4 (n=216)
Mean age *(SD)*	59.7 (2.85)	60.3 (2.80)	60.2 (2.81)	60.3 (2.92)[a]	59.9 (2.86)	60.0 (2.98)	60.5 (2.85)	60.5 (2.91)[a]
Gender %								
Male	48.0	45.3	44.1	42.4	51.2	44.4	39.0	34.7
Female	52.0	54.7	55.9	57.6[c]	48.8	55.6	61.0	65.3[b]
Ethnicity %								
White	96.6	96.9	96.6	97.0	96.3	98.4	97.1	95.3
Non White	3.4	3.1	3.4	3.0[c]	3.7	1.6	2.9	4.7[b]
Marital status %								
Married/living as married	83.7	73.6	62.1	51.4	84.2	86.9	67.4	39.5
Not married	16.3	26.4	37.9	48.6[b]	15.8	13.1	32.6	60.5[b]
Work status %								
Employed full time	35.1	25.2	14.3	8.1	35.3	38.5	28.3	16.4
Employed part time	15.0	12.1	9.5	6.1	23.2	19.0	20.3	11.7
Retired	42.4	49.1	49.3	53.3	20.0	18.7	12.8	17.8
Unemployed	7.5	13.5	26.9	32.4[b]	21.6	23.8	38.6	54.0[b]

[a]F test for difference across SES Groups $p<.01$

[b]Chi square test for difference across SES Groups $p<.01$

[c]Chi square test for difference across SES Groups $p>.05$

Table 2

Differences in dispositional optimism across the four socioeconomic status groups in the Scottish and English samples (1=highest SES and 4= lowest SES)

	Scottish sample				English sample			
	SES Group 1 (n=1293)	SES Group 2 (n=1846)	SES Group 3 (n=1891)	SES Group 4 (n=840)	SES Group 1 (n=1326)	SES Group 2 (n=1409)	SES Group 3 (n=523)	SES Group 4 (n=216)
Total dispositional optimism score *M (SD)*	21.0 (4.52)	20.2 (4.45)	18.8 (4.54)	18.1 (4.36)[a]	20.6 (4.66)	19.2 (4.52)	18.2 (4.64)	17.3 (4.55)[a]
Negative items score *M (SD)*	11.0 (2.67)	10.3 (2.82)	9.00 (3.01)	8.40 (2.93)[a]	10.8 (2.89)	9.60 (2.97)	8.54 (3.12)	7.91 (3.10)[a]
Positive items score *M (SD)*	10.0 (2.60)	9.99 (2.60)	9.80 (2.63)	9.68 (2.62)[b]	9.81 (2.58)	9.56 (2.52)	9.65 (2.72)	9.36 (2.78)[c]

[a]Test for linear trend across SES Groups $p<.001$
[b]Test for linear trend across SES Groups $p=.001$
[c]Test for linear trend across SES Groups $p=.013$

Appendix II Chapter in press: Cancer and Depression

In: Depression and Physical Illness, Ed. A Steptoe, Cambridge, Cambridge University Press

Alice E Simon, Steven C Palmer and James C Coyne

Introduction

Recent advances in the detection [1] and treatment of cancer [2] have led to longer survival times [3]. For example, the five year survival rate of localized breast cancer is now 97% [4]. As a result of this lengthened life expectancy, greater attention is now being paid to quality of life and psychosocial care for cancer patients. In the short term, this means ensuring that patients maintain their quality of life during diagnostic and treatment phases. In the longer term, the aim is to ensure that psychological problems are prevented or ameliorated so that cancer patients can rehabilitate and resume functioning at the level they maintained before their cancer.

Cancer remains a life-threatening illness linked by many with fears about incapacity, disfigurement, and death [5;6]. Unsurprisingly, many individuals diagnosed with cancer experience at least transient psychological distress. This recognition, however, can lead to a dismissal of depression as a normative response to cancer and missed opportunities to address a highly impairing, but readily treatable psychiatric disorder when depression does occur. On the other hand, overestimation of the extent to which cancer results in depression can misguide allocation of resources, leading to an emphasis on strategies for aggressively detecting psychiatric disorders, at the expense of follow-up care for patients who have already been identified, as well as

attention to more common problems and basic supportive needs that affect quality of life among cancer patients more generally.

In addition to concern about depression as an added disease burden, there is considerable speculation about depression as a cause of cancer and predictor of disease progression and survival [7]. If depression can be shown to affect progression and survival, ensuring that it is detected and effectively treated becomes all the more important. Yet, tying the value of treatment of depression to its effect on disease course and an extension of life can lead to a discrediting of quality of life as a valuable outcome for mental health and psychosocial interventions, particularly if stronger claims about effects on progression and survival are not substantiated.

The relationship between cancer and depression is the focus of a large and growing literature. A recent review identifies more than 3000 published abstracts in the years 1966 to 2001 [8]. In this chapter we will discuss three main areas: i) the prevalence of depression among cancer patients, ii) the identification and treatment of depression among cancer patients, and iii) the relationship between depression and cancer incidence, progression and survival. We propose that although the diagnosis and treatment of cancer is associated with depression for some, the prevalence of depression has been overestimated. Inaccurate estimates of the prevalence of depression impede the design of effective services and the rational allocation of clinical resources. A number of treatments for depression have been shown to be efficacious, but there remains a lack of demonstrated effectiveness in the delivery of these interventions in the routine care of cancer patients, in part because the competing demands of managing a life-threatening illness interfere with the delivery of quality care for depression. We will argue that the greatest challenge in the management of depression in cancer patients is ensuring the adequacy of the delivery

of treatment within the confines of these competing demands, rather than the lack of efficacious treatments. Finally, available data suggest a lack of support for speculations that depression causes cancer or directly accelerates its progression, but depression remains an additional disease burden and threat to quality of life.

Prevalence of Depression among Cancer Patients

Depression is widely believed to be a highly prevalent condition among cancer patients but estimates of its prevalence vary greatly. Massie's [9] review of papers published up to 2002 cites a range of 0-38% for major depression and 0-58% for depression spectrum disorders (including more mild and moderate symptom reporting of depression), both estimates are far too imprecise to provide estimates of need for services. In studies published since 2002 this variability is still common. At the lower end, one study of a breast cancer waiting-room sample found that 29% of patients were in the distressed range. Follow-up interviews found that approximately 9% met criteria for major depression, 7% met criteria for minor depression, and 6% met criteria for generalised anxiety disorder [10], quite consistent with other recent estimates [11-13]. One of the recent higher-end estimates is Burgess and colleagues' [14] report that 48% of breast cancer patients experienced "clinically significant" depression or anxiety in the first year after diagnosis. However, this figure grouped individuals meeting full diagnostic criteria for MDD and generalized anxiety disorders with "borderline" cases of depression and anxiety for which the efficacy of intervention has not been established. Burgess and colleagues note that a year after diagnosis, the prevalence of "clinically significant" depression and anxiety was only 15%, and thereafter the risk of anxiety and depression was no greater than in the general population, suggesting that the depression and anxiety being discussed is largely self-limiting and not an enduring clinical disorder.

There are a number of factors which contribute to the wide variation in reporting of depression in cancer patients. As already mentioned, levels of depression are likely to vary according to the length of time that has elapsed since diagnosis, and this may be particularly true where sub-clinical cases are concerned [e.g.14]. Higher estimates may also reflect use of self-report questionnaires of "depressive symptoms" rather than diagnostic interviews to ascertain formal clinical diagnoses [15], or the sampling of inpatients with more severe somatic disturbance or advanced stage of disease [16;17].

In UK older adults (60-74), the group most likely to experience a cancer diagnosis, the 1-month prevalence for mixed anxiety and depressive disorder is 7%, 3% for general anxiety disorder and 1% for depressive episodes [18]. Using an index of depressive symptoms and a wider age range (16-74), the one-month prevalence is 10% for all adults in the UK [19]. In the US, Kessler et al. [20] find 16.6% lifetime prevalence of depression and 6.6% 12-month prevalence. Some studies of the prevalence of depression among cancer patients report levels comparable to or lower than these, suggesting that cancer itself may provide no additional risk for depression. This hypothesis was systematically tested in a meta-analysis of 58 studies comparing levels of anxiety and depression in cancer patients to the general population. This showed that levels of depression were higher in cancer patients than in the general population but levels of anxiety and general psychological distress were not [21]. Other reviews also conclude that depression is more common in cancer patients than among the general population [8;15;22]. However, differences in sampling and assessment strategies, definitions of depression and diagnostic criteria, and handling of overlap between somatic symptoms of disease/treatment and depression make it difficult to draw definitive conclusions at this time.

Another useful comparison is between levels of depression in cancer patients and other patient groups. Rates in patients with neurological disorders appear to be more consistently higher (30-50%) than in those with cancer or other medical illnesses [9]. Analyses of a longitudinal study of depressive symptoms in a sample of 8387 adults (aged 51 to 61 years) suggested that cancer patients have more depressive symptoms than those with hypertension, arthritis, heart disease, diabetes or stroke in the first two years after diagnosis. Levels of depressive symptoms in cancer patients were comparable to levels found in those with chronic lung disease [23]. However, the age range for this study is lower than the mean age of diagnosis of most cancers, and among cancer patients, lower age is associated with greater distress. More generally, estimates of the prevalence of major depressive disorder among cancer patients based on semi-structured diagnostic interviews with representative samples overlap with the 5% to 13% range found in primary care patients [24-28]

The best estimates of the prevalence of depression in cancer patients suggest that the disorder is more common than in the general population, but perhaps only as common as, or little more common, than, general medical patients, including primary care patients. Even accepting the higher estimates of prevalence in cancer patients, the majority will not develop major depression. As Raison and Miller's [22] review concludes "cancer is a risk factor, rather than a mandate, for depression" (p283). This raises an interesting, but overlooked issue. If cancer does not raise the level of current depression as once thought what effect does it have on lifetime rates of depression? Depression is a recurrent, episodic condition with a mean first onset in the early twenties, long before the mean age at which most cancers are diagnosed. If most cases of depression during cancer treatment are recurrences, this would have important

implications for efforts to detect and treat this depression, and perhaps even prevent it among cancer patients vulnerable on the basis of past history.

Dilemmas in the Diagnosis and Assessment of Depression in Cancer Patients

Cancer poses many of the same challenges as other medical conditions in terms of accurate diagnosis of depression and the suitability of various strategies for detection and assessment. Symptoms that discriminate well between psychiatric and non-medical patients may prove less efficient in cancer patients, necessitating adjustment in diagnostic criteria. The overlap between depressive symptoms and the symptoms of cancer and side effects of treatment may pose problems in the interpretation of self-report and interview measures of depression

Controversy in the Diagnosis of Depression

Many cancer patients report symptoms of fatigue, loss of appetite and cognitive impairment that could be attributed to either the illness, side effects of treatment, or depression. It has been particularly difficult to resolve the overlap between the fatigue that accompanies treatment for cancer and depression [29]. Confusion about the overlap between the symptoms of MDD and those of cancer and its treatment could result in invalid diagnoses, leading to inappropriate treatment of non-depressed individuals with antidepressants, in lieu of more appropriate supportive services or empirically supported interventions for other forms of symptom distress [30]. The philosophy of the DSM-IV [31] definition of MDD is inclusive and non-etiological, and although the criteria for attributing a symptom to a medical illness are strict (i.e., the symptom must be the direct physiological consequence of a medical condition), the validity of this approach remains unsettled.

Studies provide contradictory suggestions as to whether overlapping symptoms should be given equal [28;32] or lesser weight [33;34;34;35]. Various strategies

have been proposed for diagnosing MDD among cancer patients [36-38]. Inclusive strategies count all symptoms, regardless of their aetiology and offer high sensitivity for MDD at the expense of low specificity and over diagnosis [e.g. 39]. Exclusive strategies allow only symptoms clearly unrelated to the diagnosis and treatment of cancer to count toward an MDD diagnosis. However, this approach may require the diagnostician to posses more knowledge than is readily available in the literature [38]. The substitutive approach [40] replaces somatic symptoms with additional cognitive symptoms. However, there are currently no clear and agreed upon guidelines as to which symptoms to replace, the symptoms that should replace these, or whether and how to weigh various symptoms to arrive at an accurate diagnosis. Etiologic approaches count symptoms only if they are clearly not a result of physical illness, and thus can be the most restrictive of the classification schemes. Indeed, prevalence rates for depression among medical samples can vary as much as 210% when comparing inclusive and etiological strategies [41]. The confusion over which strategy is most "accurate" in the sense of clinically useful remains unresolved, and existing data [39], though sparse, indicate that small changes in diagnostic strategies can substantially affect the nature and prevalence of MDD identified.

In the absence of conclusive data, the most prudent strategy may be to apply what is known about depression among other patient groups. Most cases of major depressive disorder among adults are recurrences. Among primary care patients, individuals with current depression are eight times more likely to have a history of depression than non-depressed individuals, and after taking history into account, the risk of depression proffered by other putative factors is substantially lowered [e.g. 42]. Given this, it may be most reasonable for clinicians to have a variable threshold for counting symptoms, taking an inclusive approach among individuals with a history of

depressive disorder and a more etiologic approach among those without such a history, but being prepared to revise a provisional diagnosis based on course or response to treatment. This resolution, while less than ideal, may allow for identification of those most likely to benefit from intervention while reducing the chance of introducing new treatment to individuals unlikely to benefit. Whether such a resolution can be readily implemented is unclear. It is somewhat reassuring that mental health professionals can be trained to discriminate between symptoms of depression and symptoms of physical illness and side effects of treatment when using structured interview protocols and formal diagnostic criteria [43]. On the other hand, lay interviewers required to accept patient reports at face value without probing [e.g. as in 44] produce dubious diagnoses, rendering the conclusions of some research studies suspect [45].

Prevalence of depression by cancer type, stage and treatment

Disease site

Cancer patients are not, of course, a homogeneous group in terms of the cancers they have and so for this reason alone differences exist in the levels of distress experienced by patients. Zabora et al [46] studied 5000 cancer patients, of whom 58% had received a diagnosis within the last 90 days. The highest prevalence of distress was found in lung cancer patients, where 43.4% of the sample showed high levels of distress. Similarly high levels of distress were experienced by patients with brain, liver, pancreatic and head and neck cancer. Significantly lower levels of distress were experienced in patients with gynaecological, breast, colon and prostate cancers. This may be because of the better prognosis for these cancer sites. Other studies report similar findings, for example, Stommel et al [47] found higher levels of depression in

lung cancer patients compared to breast, colon or prostate patients in their sample of 860 older (65 years+) patients.

Disease stage

Stage of disease at diagnosis is another factor that affects reporting of psychological adjustment. Being diagnosed with more advanced disease implies a poorer prognosis and understandably can be expected to pose a greater threat to psychological well-being. A number of studies show that more advanced disease is associated with increased psychological distress [e.g. 48;49;50] although other studies find little or no relationship between stage and psychological outcomes [51-53]. Studies that fail to find an effect often do not include patients with the most advanced disease stages [14;e.g.52], or make a comparison between early and advanced stage patients in widely different time frames since diagnosis [e.g. 51]. These varied responses may also reflect the fact that patients are notoriously poor at understanding the precise implication of their diagnosis [54-57].

Treatments of cancer

Some cancer treatments are also associated with increased levels of depression. Immunotherapeutic agents, such as interferon-alpha and interleukin, used to treat some cancers (e.g. kidney, melanoma), induce depressed mood as a direct side-effect [58-60]. Other more extreme treatments such as bone-marrow or stem-cell transplants appear to result in higher levels of distress than cancers with other treatment modalities indirectly because of the more severe trauma to the body and isolation of the patient [61-63]. More widespread treatments such as chemotherapy, radiotherapy or surgery commonly cause symptoms of illness including fatigue, pain and sickness. These symptoms experienced at chronic levels are debilitating and are connected to psychological distress [47;64-66]. The studies cited here find that different

treatments can increase levels of distress. Patients currently undergoing treatment may differ in terms of distress compared to those who have completed or who are still awaiting treatment. .

There are also other studies which conclude that type of treatment is not associated with distress [e.g. 14;47;53]. Burgess et al's [14] study of depression and anxiety in 222 women with breast cancer concludes that risk factors such as younger age, past-history of depression and lack of social support, are more important risk factors for depression than cancer-related variables. This possibility cannot be discussed within the parameters of this review. These variables are risk-factors for depression in general population samples.

Detection and Treatment of Depression in Cancer Patients

Regardless of the prevalence of depression, its occurrence represents a burden to the patient. Nonetheless, the clinical significance of distress remains unclear. Zabora et al. [46] suggest that 2/3 of distressed patients improve without intervention, but provide no supporting data. Others suggest that most patients experience a reduction in initial distress within weeks of diagnosis, and considerable improvement within 3-4 months[14;67-69]. At least one effort to monitor intensively the emergence of any distress and to intervene quickly failed to demonstrate an effect, apparently because of the high rate of resolution without any intervention beyond routine care [70]. Yet, there is a consensus that not all distress among cancer patients resolves so readily and that appropriately identifying and treating distressed patients is imperative. A more useful approach may be to identify groups of people who are most at risk for developing psychological problems and direct available services towards them. Unfortunately, there has not been much progress in identifying such patients.

It is well documented that depression is frequently overlooked by health care professionals, and that depression that goes undetected in routine medical care is not likely to be addressed elsewhere [71]. Cancer care professionals are often not well equipped to deal with depression in their patients, lacking the time, communication and diagnostic skills, and treatment and referral resources that are needed. Fallowfield and colleagues [72] assessed 143 cancer physicians' ability to detect distress in their patients. Over 70% (595/827) of patients with probable psychiatric morbidity (measured by GHQ-12) were missed by their physicians. Physicians and nurses are able to recognize obvious signs of distress, such as crying, but miss symptoms such as suicidal thoughts or hopelessness, that would require more involved interviewing or direct inquiry to elicit [73;74]. Undetected depression in cancer patients represents a missed opportunity to reduce suffering and impairment. This has led to a growing chorus of calls for routine screening of cancer patients for psychological distress and depression [75-77]

Screening for depression in cancer patients

Screening for depression involves patients completing self-report questionnaires or computer touch screen measures with the results being passed on to doctors or allied health professionals for follow-up evaluation, and, if appropriate, treatment or referral. Screening instruments that have been proposed range from a simple distress thermometer [e.g. 78] to the full range of standardized measures developed in other populations, such as the Center for Epidemologic Studies-Depression Scale [CES-D; 79], Brief Symptom Inventory [80], Hospital Anxiety and Depression Scale [HADS; 81]and two [82] and .nine item [83] versions of the Patient Health Questionnaire (PHQ).

With appropriate cut-off points, as few as two screening items may prove as

valid and efficient as longer instruments [84], reducing patient and staff burden. Yet, regardless of the length or other details of a screening instrument, a clinical interview is necessary to confirm a diagnosis. Conceptually, empirically, and clinically, there is a distinction between a score on a self-report measure and a clinical diagnosis of depression sufficient for decision making [25]. The imperfect fit between scores on a screening instrument and diagnosis dictates that efficient cut-points for a screening instrument inevitably involve a balance between sensitivity in identifying disorder and specificity for ruling out individuals without diagnosis. Lower cut-points ensure that fewer depressed patients are missed, but at the expense of requiring more follow-up interviews of patients who turn out not to be depressed. Resolution of these "false positive" cases is costly, and likely diverts resources from improving the treatment of individuals with known depression. In one large-scale study of depression screening in primary care settings, Spitzer et al. [85] estimated that an additional 8.4 minutes for resolution of a positive screen had to be added to what would have otherwise have been a 6 to 12 minute encounter . This observation was in the context of a research study with enriched resources and training for staff that is unlikely to be available in routine oncology settings. Other research has demonstrated that such resolution of positive screens can cost an additional US$60 per patient [86].

A study conducted by two of the authors of this chapter [10] raised some issues about the efficiency of screening. Almost one-third of a sample of women recruited from the waiting room of a specialty breast cancer treatment setting screened positive for depression, despite many of them being long-term survivors reporting for a follow-up visit. This figure could be cited as evidence of the enduring distress associated with breast cancer, but it is actually almost identical to what would be obtained in a primary care waiting room [87]. Furthermore, only 8% of the waiting room

sample was subsequently found to have MDD and the odds that an individual screening positively having MDD was only 21%. Many of the depressed women had a recent or current prescription for an antidepressant, so that the probability of an interview with a woman who screened positive would yield an untreated case of MDD was only 7%. In short, two stage screening and interviewing in this sample, could provide little in terms of improved detection of untreated depression for a lot of effort.

There is some evidence that the introduction of screening with adequate feedback to medical staff can increase the number of cases of MDD that are identified [13] and the number of patients who are referred for psychiatric care [88]. This should presumably result in a reduction in the overall level of depression in the screened sample [89]. However, there has yet been no demonstration that routine screening for depression reduces the rate of disorder or level of depressive symptoms among cancer patients on a clinic or population basis. The consistent finding in the general medical literature is that screening does not improve patient outcomes without the introduction of considerable resources, and it is exceedingly difficult to identify any enduring benefits after the enriched resources of a demonstration project are withdrawn [90]. We know of no demonstration that screening by itself reduces depression on a population basis, despite an extensive review of the literature [90]. The result of one pilot study with prostate cancer patients raises some issues that deserve more attention. Roth and colleagues [91] were able to get 77% (93/121) of a waiting room sample to complete questionnaires and 29 scored above a cut-point on one or both screening instruments. These 29 patients were referred for further evaluation, but 12 missed or refused an appointment. One recurrent issue in dealing with these patients was the difficulty of getting such an evaluation without requiring a return visit by the patient. Of the 17 evaluated, three not currently receiving treatment were given a psychiatric diagnosis.

A re-evaluation was recommended to them, but there is no report of how many completed this. Consistent with some of the difficulties Roth and his colleagues encountered, Shimizu and colleagues [88] found that only 28% (19/67) of cancer patients who scored positive on a screening test for depression accepted a referral to a psychiatrist.

Screening is clearly not a panacea in the improvement of the outcome of depression on a cancer setting or population basis. We would urge caution before any commitment to screening as the sole or primary means to address depression in a cancer care setting, and careful consideration of its likely costs, benefits, and alternatives. Maguire [92] apparently shares our concerns and recommends training cancer care professionals in better detecting distress and depression in conversations with patients. We would also recommend strategies such as greater surveillance of cancer patients with histories of depression, given the importance of this background as a predictor of depression during cancer care [93-95]; monitoring of the adequacy of existing treatment of patients identified as depressed; as well as lowering the barriers for cancer patients who are motivated to seek specialty mental health care.

Treatment for depression in cancer patients

In light of conventional assumptions that cancer is a strong risk factor for depression, it might seem ironic that there is a paucity of clinical trials examining treatment for depression in cancer patients. An expert scientific review and consensus conference commissioned by the Depression and Bipolar Support Alliance (DBSA) [96 in press] concluded that: "Available evidence strongly suggests that depression in the patient with cancer responds to TCAs, SSRIs, mirtazapine, and mianserin." (p16). Yet, this statement is based on seven studies. Two were double blind, randomized placebo controlled trials supporting the efficacy of mianserin, a heterocyclic

antidepressant that is not commonly prescribed. Beyond that, none of these studies were double blind, randomized placebo controlled trials in which an antidepressant was shown to be superior to placebo. While one randomized placebo controlled trial obtained null effects for fluoxetine [97] the lack of evidence is mainly a matter of the paucity of research with adequate statistical power and other minimal methodological rigor. Pirl [8] cites nine relevant studies, but his additions do not change our conclusion. Thus, currently, the strength of the recommendation of treatment of depression in cancer patients with antidepressants must come from studies of the treatment of depression with antidepressants more generally in the presence of co-morbid physical illness. However, the evidence is that depressed patients with co-morbid physical illness have worse treatment outcomes than those without physical co-morbidity [98].

Evidence that psychotherapy is efficacious for depression in cancer patients is similarly limited. Sheard and Maguire [99] have provided what is becoming a widely cited meta-analysis of the effects of psychological interventions on depression in cancer patients. They initially identified twenty intervention trials in which depression was measured as an outcome, but only ten allowed assessment of an effect size. Sheard and Maguire [99] found an effect size of .36, but the data were found to be highly heterogeneous, and elimination of three positive outliers with small sample sizes and other serious design flaws reduced the effect size by a half, .19. While these results can hardly be seen as demonstrating the efficacy of psychotherapy for depressed cancer patients, neither can they be taken as decisive evidence against the efficacy of treatment: particularly in this instance, absence of evidence of an effect is not evidence of an absence of effect. Sheard and Maguire [99] note that most of these studies did not involve recruitment of patients on the basis of them being depressed, and those that did so relied on self-reported distress as the criterion. What Sheard and

Maguire [99] do conclude for the studies in which patients were recruited without regard to level of depression is that there is no evidence that providing psychotherapy to non-depressed patients prevents depression.

In the midst of what may seem a discouraging assessment of the literature, it would be useful to point to a promising recent study. The Nezus and colleagues [100] randomized 132 cancer patients to either individual problem-solving therapy, problem solving therapy with the involvement of a significant other, or waiting list control. Patients were not recruited on the basis of a diagnosis of depression, but the requirement that they be experiencing a significant level of distress yielded a sample that had depressive symptoms of a mean severity typically seen in clinical trials with depressed outpatients. Both of the two problem-solving therapy conditions resulted in significant reductions in distress on most of a set of outcome measures, whereas baseline levels of distress were maintained in the waiting list control groups. The cancer patients who had the involvement of their significant others experienced greater gain than those receiving individual problem solving therapy. Improvements in the patients receiving active treatment were still evident at one year follow up.

Another promising, but preliminary study, supports patients' use of anti-depressant medication prior to receiving to treatment with interferon-α in order to prevent the development of depression, a side effect serious enough to require discontinuation of interferon in the treatment of melanoma. Musselman et al [59] conducted a double-blind study using paroxetine in malignant melanoma (N = 40) patients prior to the start of interferon-α treatment. Only 2/18 patients receiving paroxetine developed depression compared to 9/20 in the placebo group. Further, only 1 patient in the paroxetine group, compared to 7 in the placebo group, discontinued interferon treatment because of severe depression. This suggests that there may be a

role for anti-depressants as a preventative measure in patients receiving this type of treatment. These results need to be replicated and long-term effects are still unknown.

A third innovative study is more troubling in its implications, particularly given the investigators' interpretation of their results. Fisch and colleagues [101] randomized cancer patients in the community to receive by mail either fluoxetine or placebo, with the instructions that patients contact their oncologist if they experienced vomiting or nausea. Participants in this study had been screened for depression, but screening served as a basis for excluding patients who did not have at least some symptoms, rather than for insuring clinically significant levels of symptoms. The authors concluded from their results that "our data may broaden the comfort zone of oncologists for prescribing antidepressants for some patients." (p.1942). However, there were numerous methodological problems with this study, starting with difficulties accruing patients despite a statewide recruitment effort. Moreover, the differences between their intervention and placebo groups were greater at baseline than at follow up, and in the follow-up assessment on which they base their claim of effectiveness; data were available for only 14 of the 81 intervention patients and 19 of their 78 placebo patients. Our major concerns with this study are threefold [see also 102;103]. First, there is more generally a lack of evidence that antidepressants are effective for persons who have sub-threshold depression and the investigators' encouragement of such use is counter to available evidence. Secondly, it is already difficult to get non-psychiatric physicians such as oncologists to adhere to diagnostic criteria and provide adequate patient education and follow up. Fisch and colleagues imply that neither is needed. Finally, from the point of view of policy, it would be unfortunate if inaccurate claims about the effectiveness of mailing antidepressants to patients who are not even depressed were used to argue against the provision of

appropriate psychosocial services. Substantial rates of prescription of antidepressants to cancer patients who are not depressed is already an important issue in quality and economics of mental health care for cancer patients [102].

In summary, the case for the efficacy of intervention for depression among cancer patients depends mainly on evidence derived from other populations. Demonstrations that such claims can be validly extended to cancer patients are sorely overdue. However, our earlier review of the prevalence of depression among cancer patients suggests a challenge in the mounting of methodologically adequate studies: if only 9% of breast cancer patients suffer from major depression and a substantial proportion are already receiving treatment, then a multi-site trial with massive amounts of screening may be necessary to accrue a sufficient sample.

Effectiveness of Delivery versus Efficacy of Treatment of Depression in Cancer

Even if we provisionally accept that what is efficacious in the treatment of depression more generally should work for cancer patients as well, there is the question of the effectiveness with which care for depression can be delivered to cancer patients. Aside from the urgent and competing demands of treating a life-threatening illness, there are formidable issues concerning patient acceptance and access to quality care. A high proportion of patients reject psychological intervention [88;104;105]. Moynihan [104] reported that only 40% (73/184) of their sample of testicular cancer patients accepted psychological therapy. "We make a plea for caution with regard to the blind faith that counseling will be gratefully received and will be effective despite a dearth of sound evidence" (Moynihan et al., 1999, p. 128). Sharpe and colleagues [105] report that 53% of patients rejected their problem-solving intervention but 37% also rejected the control condition where there was simply monitoring of depression and 'usual care'. Sollner and colleagues [106] found that only

42% of breast cancer patients who screened positive on a measure of distress endorsed an interest in counselling, a proportion no greater than for non-distressed breast cancer patients. In the previously noted study by Roth and colleagues [91] one of the prostate patients refusing screening outright stated "This is a psychiatric evaluation? Right now I have my own problems and I don't want to get involved."

The data are mixed as to the extent to whether cancer care professionals influence patient uptake of mental health and psychosocial treatment. Although most (68%) of a sample of prostate cancer patients reported that they would prefer not to take medication for depression, 75% indicated that they would do so if advised by their physician (Shapiro, et al., 2004). However, Eakin and Strycker [107] found that while clinicians reported referring 70% of cancer patients to support services, only 24% of these patients recalled having services discussed the issue.

The problem of low uptake and even patient resistance to mental health and psychosocial services is often framed in terms of stigma, with the requisite solution being a destigmatization of help-seeking [108]. However, there is rather consistent evidence that offered a choice, cancer patients prefer more support and communication from oncologists and oncological nurses to interactions with mental health professionals, and interventions designed to increase their access to quality, understandable information about their condition and its treatment to counseling and psychotherapy [109-113]. Perhaps, not unreasonably, patients prefer to deal directly with the perceived source of their distress and depression [106]. It remains an important, but unaddressed question whether improved access to care specialists and medical information is a more acceptable and effective means of preventing and ameliorating depression than formal mental health services, or, if not, such improved access and information might function as an effective first stage response, such that patients who

do not sufficiently benefit are particularly appropriate for specialty mental health interventions.

Even when depressed cancer patients are interested in empirically supported treatments, they may have difficulty accessing such services. Cancer care tends to be provided in tertiary care settings to which patients travel many miles [10;113]. It may be logistically difficult or undesirable to coordinate mental health care with visits for chemotherapy or radiation, and unrealistic to expect that patients will make regular return visits expressly for care for depression.

Then there is the issue of the availability in cancer care settings of professionals trained in the effective treatment of depression. It has been argued that quality mental health and psychosocial care is an essential component of comprehensive cancer care, but psycho-oncology units, if they are present at all in routine cancer care, tend to be understaffed [76]. Pamphlets for the Memorial Sloane Kettering Cancer Center, which has been so instrumental in the development of psycho-oncology, flatly state that specialty psychosocial services are not available in their affiliated cancer care settings. Furthermore, the patient base needed for interventions targeting focused groups of cancer patients such as early breast or metastatic breast cancer patients has not usually been appreciated. Goodwin et al's [114] presentation of lessons learned in a randomized trial of supportive expressive therapy for metastatic breast cancer patients deserves careful consideration.

The unfortunate state of affairs for treatment of depression in routine care for cancer is that if depression is addressed at all, it is likely to be with peer or professionally led support groups with patients of varying cancer site, stage of cancer, and time since diagnosis; nonspecific individual counseling and psychotherapy; or, more predominately, prescription of antidepressants by non-psychiatric physicians

and nurses that is both nonspecific and poorly followed up. The gap in outcome is likely to be great between what occurs with these treatments and what is obtained with empirically supported treatments in the context of a clinical trial.

The Relevance of Primary Medical Care

In closing our discussion of care for depression in cancer patients, there are three reasons for giving attention to primary medical care. First, the de factor mental health system for the treatment of depression in North America and the United Kingdom centers on primary medical care [115]. Cancer patients who are suspected of being depressed are likely to be started by their oncology clinicians on antidepressants with expectations of follow up in primary care or to be referred directly to their primary care physicians for further evaluation for treatment with medication [116]. The quality of care for depression in primary care is thus likely to be the quality of care available to depressed cancer patients.

Second, over 15 years of research on treatment of outcome of depression in primary care document well the difficulties in ensuring quality of care in non-psychiatric medical settings [71;117].This large body of literature indicates that in routine primary care, treatments with established efficacy are delivered with effectiveness no greater than what is observed for placebo in clinical trials in specialty mental health settings, apparently due to the low quality of routine care. It is estimated that only 20% of depressed primary care patients receive adequate care, and there are notable deficiencies in patient education, scheduling of follow-up visits, and a failure to adjust medications in the face of unacceptable side effects or lack of improvement [71;118]. Approximately 40-50% of depressed patients will need such adjustments [119], but in the absence of adequate monitoring and follow up, problems with medication and nonadherence are not likely to be detected.

It has become clear that simply getting more depressed primary care patients identified will not improve patient outcomes on a practice or population basis, that physician education alone is insufficient to improve these outcomes [117;120], and that more fundamental changes in the structure of practice are needed. In a comprehensive review, Brody [121] has identified some components that contribute to the effectiveness of multi-component strategies to improve the outcome of depression in primary care: "we have learned that improving the care and outcomes of depression in primary care requires some or all of the following: a systematic approach to the recognition and assessment of depression; evidence-based decision support; patient education and activation; ongoing monitoring and feedback regarding patient adherence and outcomes; integration of mental health specialists for patients who are not improving as expected; and physician education" (p. 21). Brody [121] notes, however, the serious difficulties that have been encountered in attempting to sustain these innovations beyond well funded demonstration projects.

Depression management specialists, who are usually masters level nurses or social workers who take responsibility for assessment and follow up, are coming to be a basic component of cost-effective strategies for improving the outcome of depression in general medical care [122;123]. These managers can be trained to meet patient preferences by offering either medication management or brief structured psychotherapies. One promising extension of this work is the utilization of centralized systems of telephone management of depressed patients, with regular direct contact of depression management specialists with patients and support and feedback to treating professionals [124;125].

The challenges of improving the effectiveness with which depression is managed in cancer care are undoubtedly even more overwhelming than what has been

encountered in primary medical care. Yet, innovations developed in primary care are now being disseminated into cancer care, at least on a pilot and demonstration project basis. Strong et al [126] delivered a nurse-led intervention to cancer patients with a diagnosis of major depression, in which a cancer nurse was trained to deliver a problem-solving therapy and encourage the patient to consult with a primary care physician concerning antidepressants. Patients receiving the intervention showed significant reductions in depression compared to the control group. Strong et al [126] noted a number of difficulties associated with patient rejection of participation in the program and primary care physicians rejecting the advice of the depression specialists, but this pilot project nonetheless shows the promise of depression management specialists in the context of cancer care. In effort having some similarities, but with the depression management specialist having more responsibility for promoting adherence to antidepressants, Dwight-Johnson, Ell and Lee [127] randomized 55 low-income Latina patients from a public sector hospital with breast or cervical cancer and co-morbid depression to either collaborative care delivered by a depression management specialist or usual care. The usual care arm of the study involved informing the patient of her diagnosis of depression and encouraging her to seek treatment. The patients receiving the intervention experienced significantly greater reduction in depressive symptoms, which the investigators attributed to both the effectiveness of the intervention and the difficulties the control women experienced obtaining care for their depression.

Depression and cancer incidence, progression and survival: Death is not everything

The established rationale for improving the detection and treatment of depression is cancer care is that the toll of depression on the well being and quality of

life of cancer patients is unnecessary in terms of the availability of efficacious treatments. However, considerable attention has been given to controversial claims that depression is implicated in the incidence and progression of cancer, and that as demonstrated in the effects of group psychotherapy on survival, treating depression can extend the lives of cancer patients [7;96]. Indeed, the view that mood and morale affect the progression and outcome of cancer has become prevalent among the lay public and even some oncology professionals [128;129]. Yet, even the mechanism by which depression might influence development of cancer is highly speculative and controversial. Effects of depression on immune functioning is commonly cited as a plausible mechanism [7]. Yet, there are a limited range of cancers for which immune functioning is conceivably relevant, and research have consistently failed to find effects of psychosocial interventions on the immune functioning of cancer patients [130].

Spiegel and Giese-Davis [7] noted that the literature concerning depressed mood predicting cancer incidence is at best mixed, "although there is support in the literature for an association between lingering depression and faster cancer progression, the field has yet to sort out the overlapping symptoms of increased tumor burden and vegetative depression" (p.273). At the present time, there is considerable scepticism in the larger literature concerning whether a causal role for depression or emotional well-being in cancer progression can demonstrated when appropriate controls are introduced for known biological prognostic indicators, physical symptoms, and side effects of treatment [131]. Recent large scale observational studies have failed to find that emotional well-being predicts survival in metastatic [132]or early breast cancer patients [133]-[134]. In a recent review of prospective studies Garssen, [135] characterized depression as "'an influence that cannot be totally dismissed" (p.315), rather than being among the pool of the most promising psychosocial variables.

Some of the research interest in this topic stemmed from Greer, Pettingale and Morris' [136] study of survival in breast cancer patients which found an association between denial, helplessness/hopelessness, fighting spirit and survival in a group of early stage breast cancer patients. This group was followed for 15 years and the effect persisted over that time. However the sample size was relatively small (N=69). Watson et al's ongoing study of survival in breast cancer patients (N = 578) also shows that helplessness/hopelessness is related to decreased survival at both 5 years [137] and 10 years follow-up [138]. Watson et al's study fails to replicate the findings for fighting spirit found in the Greer et al study [136]. Watson et al [137] did report a very limited effect for depression at the five-year follow-up but this was no longer present at the ten year follow-up (Watson et al 2005).

As regards the possibility that psychological interventions can improve survival, Spiegel [7;139;140] has argued that there is evidence to support this possibility. Spiegel cites [7;140] five studies that support this hypothesis [139;141-144] and five studies that do not [133;145-148]. Since Spiegel and colleagues' reviews, an additional negative finding has been obtained [51]. Palmer and Coyne [149] note that three of the studies cited by Spiegel and his colleagues [142-144] involved a confounding of improved medical surveillance and more intensive medical care with psychological intervention, so that any improvement in survival cannot be unambiguously attributed to psychological intervention. The remaining two studies [139;141] have serious statistical problems. Survival data for cancer patients is highly skewed with a small number of patients typically living much longer than the rest, making medians better summary statistics than means. When the Spiegel et al [139] data are summarized in terms of median survival time, the advantage for the patients receiving the intervention is non-significant, only a few months. Fawzy et al [141] dropped a number of patients from

their analyses, including one because he was clinically depressed, and so does not provide the "intention to treat" analyses that are standard in evaluating medical interventions. Not only do available studies not support an effect of psychological intervention on survival; their relevance to the question of a role for depression in cancer progression is quite unclear. Spiegel and Giese-Davis's [7]question: "What are the aspects of psychosocial intervention that seem to be most effective in reducing depression...?" (p. 275) seemed quite unanswerable. As noted, Fawzy et al [141] dropped the one patient in his study found to be depressed, other studies do not target depression or assess it as an outcome, and, in general, these studies have recruited patients that are not notably depressed, even when suffering metastatic disease.

In summary, the evidence that depression causes cancer or accelerates its progression or that intervention for depression improves survival is largely absent or negative. This stands in sharp contrast to the robust prognostic value for depression in cardiovascular disease [150]. In the absence of credible evidence, continued claims for a role for depression in cancer and claims that psychological interventions promote survival can prove damaging to the field. "Although the prevention of death is a powerful tool to influence many of our medical colleagues who use it to justify the allocation of resources, death is not everything" [151] (p.19). When strong claims about the role of depression in cancer ultimately need to be abandoned, it will seem to be an undignified retreat to claim that the usefulness of detecting and treating depression based on the "mere" benefits for wellbeing or quality of life. An unwarranted strong claim thus could rob the credibility of what had always been a reasonable claim.

Conclusions

Depression is unlikely to cause or accelerate cancer progression. This is in contrast to depression's apparent role in other diseases, such as cardiac morbidity and

mortality discussed in chapters three and four of this book. The prevalence of depression in cancer patients is also relatively low but is an additional, and often unrecognised, problem for some patients. Difficulties assessing prevalence and identifying cases of depression in cancer patients have hampered efforts to provide appropriate clinical services. There are a number of effective treatments for depression but there is often limited availability of trained staff to deliver them and many cancer patients continue to reject interventions for psychological problems. Depression could be reduced in cancer patients by providing more effective symptom management or behavioural interventions. These forms of treatment could be more acceptable to patients and more easily delivered by existing oncology staff, but data concerning the potential of these methods are still limited.

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Appendix III – Published paper: Socioeconomic Status differences in coping with a stressful medical procedure

Socioeconomic Status Differences in Coping With a Stressful Medical Procedure

Alice E. Simon, MSc, Andrew Steptoe, PhD, and Jane Wardle, PhD

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0033-3174/05/6702-0270

Appendix IV Longitudinal questionnaire used in Study 1

FIRST, SOME QUESTIONS ABOUT YOUR GENERAL HEALTH AND ATTITUDES

Please place a cross (X) in the appropriate box

Would you say that for someone of your age your own health in general is:

Excellent ☐ Good ☐ Fair ☐ Poor ☐ 1

About how many times have you been to see your GP in the last 3 months?

Haven't been ☐ Once ☐ Twice ☐ Three or more times ☐ 2

Do you

	Yes	No
...smoke cigarettes at all nowadays?	☐	☐
...take regular exercise each week?	☐	☐

3

About how many servings of VEGETABLES do you eat *(including salad, but excluding potatoes)*? For example, a handful of carrots counts as one serving.

Less than one serving per week	One serving per week	2-4 servings per week	5-6 servings per week	One serving per day	2 servings per day	3 servings per day	4+ servings per day
☐	☐	☐	☐	☐	☐	☐	☐

About how many servings of FRUIT do you eat *(fresh, frozen or canned)*? For example, one apple counts as one serving.

Less than one serving per week	One serving per week	2-4 servings per week	5-6 servings per week	One serving per day	2 servings per day	3 servings per day	4+ servings per day
☐	☐	☐	☐	☐	☐	☐	☐

4

In general, how important do you feel the following health measures are?

	Not at all	Somewhat	Moderately	Very	Extremely
To avoid fatty foods	☐	☐	☐	☐	☐
To eat plenty of fruit	☐	☐	☐	☐	☐
To take regular exercise	☐	☐	☐	☐	☐
For women to have a cervical smear test at least every 5 years	☐	☐	☐	☐	☐
For women to have a breast screen (mammogram) at least every 3 years	☐	☐	☐	☐	☐

5

How worried are you about getting bowel cancer?

Not worried at all | A bit worried | Quite worried | Very worried

Compared with other men and women of your age, do you think your chances o getting bowel cancer are:

Much lower | A little lower | About the same | A little higher | Much higher

How worried are you about getting heart disease?

Not worried at all | A bit worried | Quite worried | Very worried

Compared with other men and women of your age, do you think your chances o getting heart disease are:

Much lower | A little lower | About the same | A little higher | Much higher

Please indicate how much you agree with each of the following items by marking the appropriate box:

	Strongly disagree	Disagree	Not sure	Agree	Strongl agree
Of all the diseases there are, I am most afraid of cancer					
I worry a lot about getting cancer					
It makes me uncomfortable to think about cancer					
Many people who get cancer can be completely cured					

In general, do you mind having medical tests?

Mind a lot | Mind a bit | Don't mind at all

YOUR ATTITUDES TO THE TEST

Since the Flexi-Scope test is fairly new, we should like to learn more about people's attitudes to it. Please indicate how much you agree or disagree with the following statements:

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
The test would give me peace of mind	☐	☐	☐	☐	☐
Having the test would take up too much time	☐	☐	☐	☐	☐
Having the test would be embarrassing	☐	☐	☐	☐	☐
Having the test would reduce my chance of getting bowel cancer	☐	☐	☐	☐	☐
The test would make me worry about cancer	☐	☐	☐	☐	☐
If I say no to the test now, I might later wish I had been tested	☐	☐	☐	☐	☐
The test would be uncomfortable	☐	☐	☐	☐	☐
The test would reassure me	☐	☐	☐	☐	☐
Having the test would be tempting fate	☐	☐	☐	☐	☐
Having the test would make me feel that I was doing something positive about my health	☐	☐	☐	☐	☐
Having the test would make me anxious	☐	☐	☐	☐	☐
I would rather let nature take its course	☐	☐	☐	☐	☐
I don't feel that I need a test	☐	☐	☐	☐	☐
I have other more important problems to deal with right now	☐	☐	☐	☐	☐
I would rather not know about problems until I have to	☐	☐	☐	☐	☐
I would not want to have a test in that part of my body	☐	☐	☐	☐	☐
It's not worth having the test because "what will be will be"	☐	☐	☐	☐	☐

Please mark the box which best applies to you:

	Not at all or rarely	Sometimes	Often	Most of the time
Do you worry about your health?	☐	☐	☐	☐
If you have an ache or pain do you worry that it may be caused by a serious illness?	☐	☐	☐	☐
Do you find it difficult to keep worries about your health out of your mind?	☐	☐	☐	☐
When you read or hear about an illness on TV or radio, does it make you think you may be suffering from that illness?	☐	☐	☐	☐

For each of the following statements, please mark the box which best applies to you

	Completely false	Somewhat false	Somewhat true	Completely true
If I were sick and needed someone to drive me to the doctor, I would have trouble finding someone	☐	☐	☐	☐
There is at least one person I know whose advice I really trust	☐	☐	☐	☐
There isn't anyone I feel comfortable talking to about personal problems	☐	☐	☐	☐
I regularly meet or talk with my friends or members of my family	☐	☐	☐	☐

Because we are studying bowel screening, we would like to know how often people get these bowel symptoms and bowel problems. In the LAST THREE MONTHS have you...

	No	Occasionally	Frequently
been constipated?	☐	☐	☐
had haemorrhoids (piles)?	☐	☐	☐
had diarrhoea?	☐	☐	☐
been troubled with wind?	☐	☐	☐
had pains in the abdomen (gut)?	☐	☐	☐
had bowel incontinence?	☐	☐	☐
noticed blood in your stools?	☐	☐	☐

Please note: If you have symptoms persistently, you should go to your GP for advice

THESE ARE SOME GENERAL QUESTIONS ABOUT YOUR MOOD AND OUTLOOK ON LIFE, BECAUSE WE KNOW THESE CAN AFFECT PEOPLE'S ATTITUDES TO THEIR HEALTH AND TO SCREENING

Please read each statement, and then mark the appropriate box for each question to indicate how you feel right now, at this moment:

	Not at all	Somewhat	Moderately	Very much
I feel calm	☐	☐	☐	☐
I am tense	☐	☐	☐	☐
I feel upset	☐	☐	☐	☐
I am relaxed	☐	☐	☐	☐
I feel content	☐	☐	☐	☐
I am worried	☐	☐	☐	☐

14

Please indicate how much you agree with each of the following items by marking the appropriate box:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I like to get all the medical information that I can	☐	☐	☐	☐	☐
There are many things I care about more than my health	☐	☐	☐	☐	☐
I do not wish to know what is going on inside my body	☐	☐	☐	☐	☐
There is too much information around about health nowadays	☐	☐	☐	☐	☐
I am never really convinced by what the doctor tells me	☐	☐	☐	☐	☐
Good health is only of minor importance in a happy life	☐	☐	☐	☐	☐
There are few things more important than good health	☐	☐	☐	☐	☐
I am interested in hearing about important medical advances	☐	☐	☐	☐	☐
I enjoy watching medical programmes on television	☐	☐	☐	☐	☐
If you don't have your health you don't have anything	☐	☐	☐	☐	☐
I usually ask the doctor or nurse lots of questions about the procedures during a medical examination	☐	☐	☐	☐	☐

15

FINALLY, A FEW QUESTIONS ABOUT YOURSELF AND YOUR FAMILY TO HELP US ANALYSE THE RESULTS OF THE SURVEY

Have any members of your family (BLOOD relatives, not relatives by marriage) had bowel cancer?

	Yes	No	Don't know
mother	☐	☐	☐
father	☐	☐	☐
mother's mother	☐	☐	☐
mother's father	☐	☐	☐
father's mother	☐	☐	☐
father's father	☐	☐	☐

	Yes	No	Don't know	Not applicable
son(s)	☐	☐	☐	☐
daughter(s)	☐	☐	☐	☐
sister(s)	☐	☐	☐	☐
brother(s)	☐	☐	☐	☐
aunt(s), uncle(s) (blood relatives)	☐	☐	☐	☐

If **YES**, number of aunts, and uncles affected ☐☐

What is your marital status?

Married/living as married ☐ Divorced ☐ Separated ☐ Widowed ☐ Single ☐

Do you have any educational qualifications? (e.g. School Certificate, GCE O' Levels, etc.)

No ☐ Yes ☐

Do you have a paid job or do any paid work?

No, retired ☐ No, not working at present ☐ Yes, part-time ☐ Yes, full-time ☐

Do you own or rent your home? Own it/buying it ☐ Rent it ☐ Other ☐

Does your household have a car? No ☐ Yes, 1 ☐ More than 1 ☐

Which of these best describes your ethnic background?

White ☐ Black ☐ Asian ☐ Other ☐ Do not wish to answer ☐

17

	Yes	No
Did you find this questionnaire easy to complete?	☐	☐
Did you mind completing this questionnaire?	☐	☐

18

Thank you very much for your help

Appendix V Post-FS questionnaire used in Study 1

FLEXI-SCOPE *trial*

Your views on the Flexi-Scope Test

You recently had the new Flexi-Scope test. Here are a few questions about what you thought of it.

Your answers will be treated in strict confidence and will help us improve the test and the information we give to others.

Please return the questionnaire in the enclosed envelope. No stamp needed.

If you have any questions please contact:

Dr
Tel:

Imperial Cancer Research Fund

THE FLEXI-SCOPE TEST

(Please tick your answers)

How satisfied were you with the INFORMATION you were given before your test?

Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied ☐

If you think the information could be improved, please tell us how:

1

How satisfied were you with the FACILITIES at the Flexi-Scope unit?

Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied ☐

If you think the facilities could be improved, please tell us how:

2

How satisfied were you with the ATTITUDE of the staff at the unit?

Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied ☐

If you think the attitude of the staff could be improved, please tell us how:

3

How satisfied were you with the way the results were EXPLAINED to you?

Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied ☐

If we could improve the way we explain the results to you, please tell us how:

4

Did you have the opportunity to ask all the questions you wanted to? Yes ☐ No ☐

5

DURING THE FLEXI-SCOPE TEST

During your test, did you feel "in control" of what was happening to you?

Very much in control	Partly in control	Not in control
☐	☐	☐

How much embarrassment did you feel during your Flexi-Scope test?

None	Mild embarrassment	Quite a lot of embarrassment	Severe embarrassment
☐	☐	☐	☐

How much pain did you feel during your Flexi-Scope test?

None	Mild pain	Quite a lot of pain	Severe pain
☐	☐	☐	☐

How did you feel when you received the results of your Flexi-Scope test?

6

Did you feel anxious...?	Not at all	Somewhat	Moderately	Very
when you received the information about the Flexi-Scope test?	☐	☐	☐	☐
in the days before your Flexi-Scope test?	☐	☐	☐	☐
about administering the enema?	☐	☐	☐	☐
about the possible effects of the enema?	☐	☐	☐	☐
whilst waiting in the clinic for your test?	☐	☐	☐	☐
during the test?	☐	☐	☐	☐

7

Compared to other men and women of your age, do you think your chances of getting bowel cancer are:

Much lower	A little lower	About the same	A little higher	Much higher
☐	☐	☐	☐	☐

Compared to other men and women of your age, do you think your chances of getting heart disease are:

Much lower	A little lower	About the same	A little higher	Much higher
☐	☐	☐	☐	☐

8

How worried are you about getting....	Not worried at all	A bit worried	Quite worried	Very worried
bowel cancer?	☐	☐	☐	☐
bowel polyps?	☐	☐	☐	☐
heart disease?	☐	☐	☐	☐
(for women) breast cancer?	☐	☐	☐	☐
(for men) prostate cancer?	☐	☐	☐	☐
ill health in general?	☐	☐	☐	☐

9

Please read each statement, and then mark the appropriate box for each question to indicate how you feel right now, at this moment:

	Not at all	Somewhat	Moderately	Very much
I feel calm	☐	☐	☐	☐
I am tense	☐	☐	☐	☐
I feel upset	☐	☐	☐	☐
I am relaxed	☐	☐	☐	☐
I feel content	☐	☐	☐	☐
I am worried	☐	☐	☐	☐

10

AFTER THE TEST

Did you have any problems after the test? Yes ☐ No ☐

If YES, what problems did you have?

When did the problems start? Immediately ☐ Within a week ☐ Within a month ☐ After a month ☐

How long did they last in total?

Do you still have problems? Yes ☐ No ☐

If YES, what problems do you have?

Did you need to contact your GP or Hospital as a result of these problems? Yes ☐ No ☐

If so, which? GP ☐ Hospital ☐

Did you have any treatment for these problems? Yes ☐ No ☐

If YES, what treatment did you have?

11

In the LAST 3 MONTHS have you...	No	Occasionally	Frequently
been constipated?	☐	☐	☐
had haemorrhoids (piles)?	☐	☐	☐
had diarrhoea?	☐	☐	☐
been troubled with wind?	☐	☐	☐
had pain in the abdomen (gut)?	☐	☐	☐
had bowel incontinence?	☐	☐	☐
noticed blood in your stools?	☐	☐	☐

Please note: If you have symptoms persistently, you should go to your GP for advice 12

OTHER MEDICAL PROBLEMS

	Yes	No
Have you had any other medical problems since the test?	☐	☐
If YES, what medical problems have you had?		

13

THESE QUESTIONS ARE SIMILAR TO SOME YOU MAY HAVE BEEN ASKED BEFORE. WE NEED YOUR ANSWERS NOW THAT YOU HAVE HAD YOUR TEST.

Please indicate how much you agree or disagree with the following statements	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
The test gave me peace of mind	☐	☐	☐	☐	☐
Having the test took up too much time	☐	☐	☐	☐	☐
Having the test reduced my chance of getting bowel cancer	☐	☐	☐	☐	☐
The test made me worry about cancer	☐	☐	☐	☐	☐
I made the right decision to take the test	☐	☐	☐	☐	☐
The test reassured me	☐	☐	☐	☐	☐
Having the test was tempting fate	☐	☐	☐	☐	☐
I would rather have let nature take its course	☐	☐	☐	☐	☐
Having the test made me feel that I was doing something positive about my health	☐	☐	☐	☐	☐
Having the test made me anxious	☐	☐	☐	☐	☐
I regret having had a test in that part of my body	☐	☐	☐	☐	☐
A screening test for bowel cancer is important	☐	☐	☐	☐	☐

14

In the LAST THREE MONTHS have you....	Better/more than usual	Same as usual	Less than usual	Much less than usual
been able to concentrate on whatever you're doing?	☐	☐	☐	☐
felt that you were playing a useful part in things?	☐	☐	☐	☐
felt capable of making decisions about things?	☐	☐	☐	☐
been able to enjoy your day to day activities?	☐	☐	☐	☐
been able to face up to your problems?	☐	☐	☐	☐
been feeling reasonably happy all things considered?	☐	☐	☐	☐
	Not at all	**No more than usual**	**Rather more than usual**	**Much more than usual**
lost much sleep over worry?	☐	☐	☐	☐
felt constantly under strain?	☐	☐	☐	☐
felt you couldn't overcome your difficulties?	☐	☐	☐	☐
been feeling unhappy and depressed?	☐	☐	☐	☐
been losing confidence in yourself?	☐	☐	☐	☐
been thinking of yourself as a worthless person?	☐	☐	☐	☐ 15

Do you think that your experience of having the Flexi-Scope test has....	Not at all	A little bit	Quite a bit	A great deal
given you a sense of reassurance that you do not have bowel cancer?	☐	☐	☐	☐
made you feel more able to do the things that you normally do?	☐	☐	☐	☐
made you feel more hopeful about the future?	☐	☐	☐	☐
made you feel less anxious about bowel cancer?	☐	☐	☐	☐
made you get on better with those around you?	☐	☐	☐	☐
given you a greater sense of well being?	☐	☐	☐	☐ 16

	Yes	No	Not sure
On balance, were you glad you had the test?	☐	☐	☐

If a friend asked you if they should have the Flexi-Scope test, would you encourage or discourage them?

Strongly encourage	Encourage	Neither	Discourage	Strongly discourage
☐	☐	☐	☐	☐ 17

FINALLY, SOME QUESTIONS ABOUT YOUR CURRENT HEALTH BEHAVIOURS AND ATTITUDES

About how many times have you been to see your GP in the last 3 months?

Haven't been	Once	Twice	Three or more times
☐	☐	☐	☐

Would you say that for someone of your age your own health in general is:

Excellent	Good	Fair	Poor
☐	☐	☐	☐

18

Do you....

	Yes	No
smoke cigarettes at all nowadays?	☐	☐
take regular exercise each week?	☐	☐

19

About how many servings of VEGETABLES do you eat *(including salad, but excluding potatoes)*? For example, a handful of carrots counts as one serving.

Less than one serving per **week**	One serving per **week**	2-4 servings per **week**	5-6 servings per **week**	One serving per **day**	2 servings per **day**	3 servings per **day**	4+ servings per **day**
☐	☐	☐	☐	☐	☐	☐	☐

About how many servings of FRUIT do you eat *(fresh, frozen or canned)*?
For example, one apple counts as one serving.

Less than one serving per **week**	One serving per **week**	2-4 servings per **week**	5-6 servings per **week**	One serving per **day**	2 servings per **day**	3 servings per **day**	4+ servings per **day**
☐	☐	☐	☐	☐	☐	☐	☐

20

In general, how important do you feel the following health measures are?

	Not at all	Somewhat	Moderately	Very	Extremely
To avoid fatty foods	☐	☐	☐	☐	☐
To eat plenty of fruit	☐	☐	☐	☐	☐
To take regular exercise	☐	☐	☐	☐	☐
For women to have a cervical smear test at least every 5 years	☐	☐	☐	☐	☐
For women to have a breast screen (mammogram) at least every 3 years	☐	☐	☐	☐	☐

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IF YOU HAVE ANY FURTHER COMMENTS REGARDING THE TEST OR THIS QUESTIONNAIRE PLEASE USE THE SPACE BELOW *(and continue on the back if necessary)*

Appendix VI: Paper submitted for publication: Disease stage and psychosocial outcomes in colorectal cancer

Submitted to: *Psychooncology*

Alice E. Simon MSc[1], Michael R. Thompson[2] M.D., Karen Flashman BSc[2] and Jane Wardle Ph.D.[1]

[1] Cancer Research UK Health Behavior Unit, Department of Epidemiology and Public Health, University College London

[2]Colorectal Unit, Surgical Department, Queen Alexandra Hospital, Portsmouth

ABSTRACT

Background: Disease stage is a strong predictor of cancer survival and therefore assumed to influence psychosocial outcomes. However, existing findings are inconsistent, perhaps reflecting limited sample sizes, especially among patients with advanced disease. There has also been an emphasis on breast cancer, resulting in a focus on outcomes among women. The present study investigated associations between disease stage and psychosocial outcomes in 110 patients diagnosed with colorectal cancer. *Methods*: Patients diagnosed within the past year in a single hospital were invited to participate in a questionnaire study and give permission for staging information to be obtained from their medical records. The questionnaire included measures of anxiety, depression, quality of life, social support, social difficulties, and quality of medical interactions. *Results*: Patients with more advanced disease were more anxious ($p<0.01$) and depressed ($p<0.001$), perceived their social support as lower ($p<0.01$), and had a worse quality of life ($p<0.01$). Women with advanced disease had more severe colorectal symptoms ($p<0.01$), and worse physical ($p<0.01$) and emotional ($p<0.05$) quality-of-life than men. *Conclusions*: Patients with advanced colorectal cancer have unmet psychosocial needs. Women may be more strongly affected by advanced disease than men.

DISEASE STAGE AND PSYCHOSOCIAL OUTCOMES IN COLORECTAL CANCER

Receiving a cancer diagnosis represents an enormous psychological challenge. Estimates vary as to the number of people with cancer who develop symptoms of anxiety (2%-25%) (Stark and House, 2000) or depression (20%-50%) (Bottomley, 1998; McDaniel et al., 1995), but it is likely that rates are higher than the 7% seen in the same age group in the general population (Evans et al., 2003).

Disease stage is widely assumed to be a determinant of psychosocial outcomes. Its prognostic significance influences the magnitude of psychological threat posed by the disease. Advanced disease stage is likely to be associated with increases in uncomfortable physical symptoms that could influence psychosocial wellbeing. Patients with advanced disease are also are more likely to receive chemotherapy, which can be physically as well as psychologically difficult to deal with. Most of the body of work on the psychosocial consequences of cancer has focused on psychosocial distress among women with breast cancer and the research findings have been mixed. Some studies have shown advanced disease to be associated with poorer psychological wellbeing (Gallagher et al., 2002; Osborne et al., 2003; Rosenfeld et al., 2004; Shimozuma et al., 1999), but others have found little or no relationship (Bleiker et al., 2000; Burgess et al., 2005; Kissane et al., 2004).

Very few studies have examined the psychosocial consequences of advanced colorectal cancer. In one early study, (Norum, 1997) reported that colorectal cancer patients with Dukes' C diagnosis (positive lymph nodes) were no more distressed than patients with a Dukes' B (cancer contained within the bowel wall), but the sample size was small ($N = 64$) and groups with stage C1 (positive lymph nodes, but cancer

contained within the bowel wall) and stage C2 disease (positive lymph nodes and cancer spread outside bowel wall) were combined, despite very different prognoses. Another study, designed to validate the Functional Assessment of Cancer Therapy – Colorectal version (FACT-C) (Ward et al., 1999) explored disease stage in relation to quality of life in two separate samples. In the Spanish sample ($N = 93$), patients with regional and distant metastases had worse quality of life compared to those with localized disease, but in the English sample ($N = 63$) the association was not significant, although the trends were in the same direction.

Another limitation to the literature on disease stage and psychosocial wellbeing is the focus on emotional distress (e.g. anxiety and depression) and quality of life. The psychosocial effects of a diagnosis of cancer can extend beyond the psychological domain. Cancer can affect social relationships (Northouse et al., 2000) which may in turn influence the support the patient receives during their illness (Reynolds and Perrin, 2004). New relationships with medical staff have to be formed and the quality of these relationships is another significant factor in coping with the disease (Ong et al., 2000). Cancer and its treatments can also impose a variety of physical and functional disabilities that compromise the patient's ability to work or to maintain independence (Wright et al., 2002). A recent qualitative study of colorectal cancer patients' experiences found that a wide range of factors were important for determining wellbeing (Dunn et al., 2006). These included satisfaction with the health system, social support from friends and family and impact on lifestyle; demonstrating that a broader conception of psychosocial wellbeing needs to be considered.

The present study was designed to examine the association between disease stage and a range of psychosocial outcomes in a mixed-sex sample of colorectal

cancer patients. We hypothesized that patients with advanced disease would have poorer psychosocial outcomes across all domains.

METHOD

Design and Procedure

This was a cross-sectional survey sampling all patients who received a diagnosis of colorectal cancer at a single hospital in Southern England over a one-year period (July 2002-July 2003, $N = 231$). Patients were sent an introductory letter with an information sheet and questionnaire. Hospital staff sent out the letters which were returned anonymously to the research staff. Questionnaires were numbered and linked to details in the hospital database to allow the hospital staff to send a reminder to non-responders after a month. Return of the questionnaire was taken as consent to the questionnaire phase of the research but additional formal consent was sought for access to the medical records.

Ethical approval was obtained from the Isle of Wight, Portsmouth and South East Hampshire Local Research Ethics Committee.

Participants

290 patients with colorectal cancer had attended the participating hospital over the trial period, of which 231 were alive at the time of the survey. Patients' GPs were contacted one month prior to the survey to allow them to exclude patients who were too ill to participate; this resulted in 19 exclusions. 212 patients were therefore sent a postal questionnaire, of which 11 declined participation, citing reasons ranging from feeling too unwell, to feeling too well and not wanting to be reminded about cancer and a further 73 did not respond. In total 128/212 (60.4%) people completed and returned the questionnaire.

Measures

Diagnostic staging

Disease staging was based on the Dukes' classification system with data taken from patients' medical records: Dukes' stage A: the tumor penetrates the mucosa of the bowel wall but no further, Stage B: the tumor penetrates into and/or through the muscular layer of the bowel wall, Stage C1: the tumor penetrates into, but not through, the muscular layer of the bowel wall and there is evidence of colon cancer in the lymph nodes, Stage C2: the tumor penetrates the muscular layer of the bowel wall and there is evidence of cancer in the lymph nodes, and Stage D: the cancer has spread throughout the body and there are distant metastases (e.g. in liver or lung).

Psychological Distress

Depression was measured with the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977), which asks about feelings over the past week. We used the shorter 10-item version (Kohout et al., 1993) but retained the original response options (four options from 'rarely, none of the time' to 'most or all of the time') rather than the 'yes/no' format. Items are summed to give scores from 0 to 30, with higher scores indicating more depression. The scale had good internal reliability in this sample ($\alpha = 0.83$).

Anxiety was assessed using the anxiety scale from the Hospital Anxiety and Depression Scale (HADS-A, 7 items) (Zigmond and Snaith, 1983). Participants rate how they have usually felt over the past week. Each item has four response options that vary slightly according to the statement. The scale range is from 0 to 21 with higher scores indicating more anxiety. Reliability in this sample was good ($\alpha = 0.87$).

Quality of Life

Quality of life was assessed using the Functional Assessment of Cancer Therapy Colorectal version (FACT-C) (Ward et al., 1999). This has five subscales: physical (7 items), functional (7 items), social/family (7 items), emotional well-being (6 items) and a colorectal-specific subscale (7 items) looking at colorectal symptoms such as control of bowels, appetite and digestion. The items ask how true each statement has been during the past seven days. The scale range is 0 to 24 for the 6-item scale and 0 to 28 for the 7-item scales, with higher scores indicating better quality of life. A total score is computed from the sum of the physical, functional, social/family and emotional subscales, with a range from 0 to 108.

Social Support

Social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet et al., 1988). The MSPSS is a measure of the subjective assessment of social support adequacy. It is a 12-item scale with three subscales (4 items each) examining support from family, friends, and significant other. Respondents are asked how much they agree or disagree with each statement. The scale range is 1 to 60 with higher scores indicating better support.

Social Difficulties

The Social Difficulties Inventory (Wright et al., 2005) is a 21-item questionnaire covering problems in managing personal care, domestic chores and responsibilities, finances and benefits, employment, relationships, sexuality and body image, mobility and leisure activities. Respondents indicate whether they have experienced any difficulties over the past month (using a range from 'no difficulty' to 'very much'). The scale range is 0 to 63 with higher scores indicating more social difficulties.

Medical Interactions

Communication with medical staff was assessed using the 4-item subscale from the Cancer Evaluation and Rehabilitation System – Short Form (CARES-SF) (Schag and Heinrich, 1988). The items refer to levels of information provided, understanding the information provided, levels of control over treatment, and difficulty asking questions. Respondents are asked how much each statement applies to them during the past month (Schag and Heinrich, 1988). Higher scores indicate poorer communication with medical staff. The subscale has reasonable internal reliability ($\alpha = 0.67$), good test-retest reliability (86% agreement) and good concurrent validity with related measures (Schag et al., 1991).

ANALYSES

Data were analyzed using analysis of covariance with disease stage as the independent variables and age and chemotherapy treatment as control variables. Outcomes included psychological distress, quality of life, social support, social difficulties and medical interactions. Missing data on individual questionnaire items were replaced using the individual's mean for each subscale if at least half the items had been completed (Fairclough and Cella, 1996).

RESULTS

128/212 (60.4%) questionnaires were returned. Respondents were 52% male (N = 65) and 48% female (N = 60), with three having missing gender information, and all were white. The mean age was 70.2 (SD = 10.7), with a range from 36 to 89. The majority were married (N = 83), 29 were widowed, and 13 were either single or divorced. Three participants did not provide information on marital status. In terms of socioeconomic status (SES), nearly half the participants (46%, N = 59) had no formal educational qualifications, although 75% (N

= 96) were home owners and 75% (N = 95) owned one or more cars. Using the limited data available on the full sample, there were no differences between responders and non-responders in terms of age, gender or residential area deprivation (Townsend index; Townsend et al., 1988).

Disease stage was indexed using the Dukes' classification system with data taken from medical records. Ten participants did not give consent for their medical records to be examined. Staging information was not obtained for two patients who had declined treatment and one who did not have surgery because of co-morbid disease. Another four patients were excluded because they had anal squamous cancers and a further one because the diagnosis was appendiceal cancer. Disease stage information was therefore available for 86% (110/128) of participants (see Table 1). The majority of participants (64%) had a Dukes' stage B or C1 diagnosis, but 11 (10%) participants had a stage D diagnosis or were receiving palliative care and 12 (10.9%) participants had a stage C2 diagnosis; these two latter categories were combined to form the 'advanced disease' category in the subsequent analyses.

Age, gender, marital status, and SES (indexed by level of education, car and home-ownership) were not related to disease stage. The average time between diagnosis and completing the questionnaire was 257 days (SD = 112 days). Time since diagnosis was not related to disease stage.

At the time of completing the questionnaire, 106/128 (83%) patients had undergone surgery, 34/128 (27%) had received chemotherapy and 22/128 (17%) had received radiotherapy. There was no association between disease stage and undergoing surgery or radiotherapy, but patients with more advanced disease were more likely to receive chemotherapy (χ^2 (1) = 12.64, p<0.001).

Patients with more advanced disease had poorer quality of life for all except one of the FACT-C subscales (see Table 2). They had worse physical well-being (F (1,108) = 2.04 p<0.05), functional well-being (F (1,109) = 3.33 p<0.01), emotional well-being (F (1,109) = 4.56 p<0.01), and colorectal symptoms (F (1.109) = 2.18 p<0.05), and a much lower overall score FACT-C score (F (1,108) = 5.15 p<0.01). The only scale that did not show differences

was the social/family subscale. More advanced disease stage was related to the perception of receiving less social support (overall MSPSS score: $F(1,107) = 3.63$ $p<0.01$) particularly from 'significant others' ($F(1,106) = 4.16$ $p<0.01$) and 'family' ($F(1,106) = 3.47$,$p<0.05$), although there was no difference in perceived support from friends. Patients with more advanced disease were also more anxious ($F(1,108) = 3.70$ $p<0.01$) and depressed ($F(1,108) = 6.76$ $p<0.001$). Quality of medical interactions and reporting of social difficulties did not differ significantly by disease stage.

Pairwise comparisons using the adjusted means showed that for the majority of the psychosocial outcomes, patients with stage A or B diagnoses significantly differed from those with stage C2/D. There was one exception to this pattern: for perceived family support the difference was between patients with stage B and stage C1 disease (mean difference = 2.22, $p<0.05$). The partial eta squared statistic (Table 1) indicates the proportion of variance in the dependent variable explained by the factor and is a measure of effect size. Effect sizes ranged from small (from 0.01 to 0.08) to medium (from 0.09 to 0.24) on the basis of squaring Cohen's r criteria for small, medium and large effect sizes (Cohen, 1988).

Men and women did not differ in age or treatments received and there were no simple associations between gender and psychosocial outcomes. However there were some significant interactions between disease stage and gender for psychosocial outcomes. Because men were more likely to be high SES (71%) than women (29%) (χ^2 (2) = 7.05, $p<0.05$) and more likely to be married (78% vs 52%) (χ^2 (2) = 9.43, $p<0.01$), these factors were controlled for in the analyses of gender differences. Among patients with C2/D diagnoses, women had worse quality of life for three of the subscales than men in terms of colorectal symptoms ($F(3,101) = 4.00$, $p<0.01$, partial eta^2 = 0.119) (see Figure 1), physical ($F(3,99) = 4.32$, $p<0.01$, partial eta^2 = 0.130) (see Figure 2) and emotional ($F(3,100) = 3.70$, $p<0.05$, partial eta^2 = 0.112) (see Figure 3). Effect sizes were in the medium range.

DISCUSSION

The results of this study showed that patients with colorectal cancer in advanced stages (Dukes' stage C2, D and those receiving palliative care) had worse outcomes than those with localized disease for almost every psychosocial outcome that we assessed. Existing studies in this area have focused primarily on breast cancer patients and the conclusions have been inconsistent, perhaps because patients with advanced disease are often examined separately and not compared to patients with other disease stage diagnoses (Pinder et al., 1993). There is also a general difficulty in recruiting patients with advanced disease into studies (Bleiker et al., 2000). In our study, patients with a C2 or D diagnosis – those with metastatic disease or in palliative care - had incrementally poorer outcomes compared with the differences between the other stages. These results highlight the importance of including patients with advanced disease in comparative research studies.

Because colorectal cancer is a disease affecting men and women we were able to examine gender differences in the relationship between disease stage and psychosocial outcomes. Women's physical wellbeing appeared to be more adversely affected by advanced disease stage than men, although because there are differences in symptoms and treatments by cancer site which could affect men and women differently, these results may not generalize beyond colorectal cancer patients.

The study had limitations. The sample size, though larger than many, was still relatively small, and like other researchers, we had difficulties recruiting participants with advanced disease. The proportion of patients with advanced disease (16%) is slightly lower than the overall colorectal cancer population, where as many as 20% of patients present with Dukes' stage D (Hardcastle et al., 1996). Disease stage information was not available for non-responders because of patient confidentiality, but it is likely that more of them had advanced disease. The overall response rate was only moderate (60%), although there were no differences between responders and non-responders in terms of age, gender or residential area deprivation, but it is hard to see that this is likely to bias the findings. The sample lacked ethnic heterogeneity, reflecting the characteristics of the area around the hospital, which may

limit the generalisability of the findings. We acknowledge the need to replicate these results and recognize the need for longitudinal research designs to examine adjustment over time.

Despite the limitations, this study is one of the first to provide strong evidence that the psychosocial burden of colorectal cancer is significantly greater in those with more advanced disease and that the problem may be more severe for women. The implication of these results is that there may be significant unmet psychosocial needs in patients with advanced disease and future research should focus on the value of providing additional social and emotional support.

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Table 1 Disease stage and treatments received at the time of the survey

		N (N = 128)	%
Disease stage	A	17	13.3
	B	41	32.0
	C1	29	22.7
	C2	12	9.4
	D and palliative	11	8.6
	Exclusions and refusals	18	14.1
Treatment	Surgery	106	82.8
	Radiotherapy	22	17.2
	Chemotherapy	34	26.6

Table 2 The relationships between psychosocial outcomes and disease stage, controlling for age and chemotherapy treatment

Dependent Variables	Disease Stage - Mean (95% CI)				Linear Univariate ANOVA P-value	Partial eta squared
	A (n = 17)	B (n = 41)	C1 (n = 29)	C2/D/Palliative (n = 23)		
Quality of Life						
Physical	24.5 (22.2-26.8)	24.4 (23.0-26.0)	23.2 (21.4-25.1)	21.4 (19.3-23.4)	P = 0.039	0.057
Functional	22.1 (19.1-25.1)	21.3 (19.4-23.3)	19.0 (16.6-21.4)	16.6 (14.0-19.2)	P = 0.005	0.088
Emotional	20.5 (18.2-22.8)	20.7 (19.2-22.2)	18.5 (16.7-20.3)	16.2 (14.2-18.2)	P = 0.003	0.117
Social/Family	21.5 (18.9-24.2)	23.4 (21.6-25.1)	19.6 (17.5-21.7)	20.4 (18.1-22.7)	P = 0.212	0.072
Colorectal	22.2 (19.5-24.8)	21.1 (19.4-22.9)	20.1 (18.0-22.2)	17.8 (15.5-20.2)	P = 0.018	0.059
Overall	88.6 (81.2-96.0)	89.8 (84.9-94.6)	80.2 (74.2-86.2)	74.5 (68.0-81.0)	P = 0.002	0.131
Social Support						
Family	18.8 (17.2-20.5)	18.7 (17.7-19.7)	16.4 (15.2-17.6)	16.9 (15.6-18.2)	P = 0.019	0.094
Friends	17.3 (15.7-18.9)	17.6 (16.6-18.6)	16.2 (15.0-17.5)	16.0 (14.6-17.2)	P = 0.100	0.048
Significant Other	19.4 (17.9-20.9)	19.1 (18.1-20.0)	17.5 (16.4-18.7)	16.6 (15.3-17.8)	P = 0.002	0.111
Overall	55.5 (51.5-59.6)	55.3 (52.7-57.8)	50.1 (47.0-53.3)	49.3 (46.0-52.7)	P = 0.007	0.097
Psychological Distress						
Anxiety	2.6 (0.6-4.5)	3.1 (1.8-4.3)	4.3 (2.8-5.8)	6.2 (4.6-7.9)	P = 0.004	0.098
Depression	2.5 (0.0-5.0)	4.5 (3.0-6.1)	6.6 (4.7-8.5)	9.6 (7.4-11.7)	P = 0.000	0.166
Medical Interactions	0.3 (0.0-0.7)	0.2 (0.0-0.4)	0.3 (0.1-0.6)	0.6 (0.3-0.9)	P = 0.219	0.041
Social Difficulties	5.8 (2.3-9.2)	5.7 (3.5-8.0)	8.6 (5.9-11.4)	9.0 (6.0-12.1)	P = 0.091	0.041

Figure 1

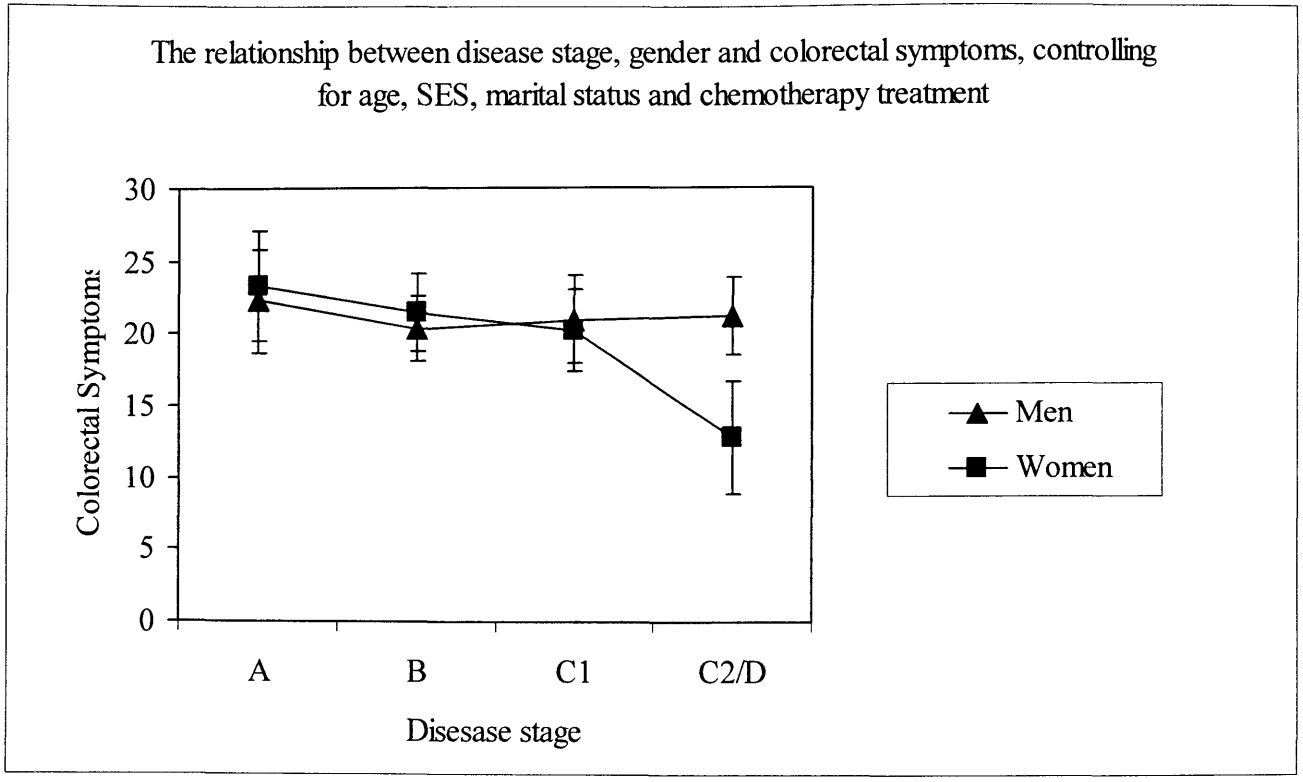

The relationship between disease stage, gender and colorectal symptoms, controlling for age, SES, marital status and chemotherapy treatment
Colorectal Symptoms
30
25
20
15
10
5
0
A
B
C1
C2/D
Disesase stage
Men
Women

Figure 2

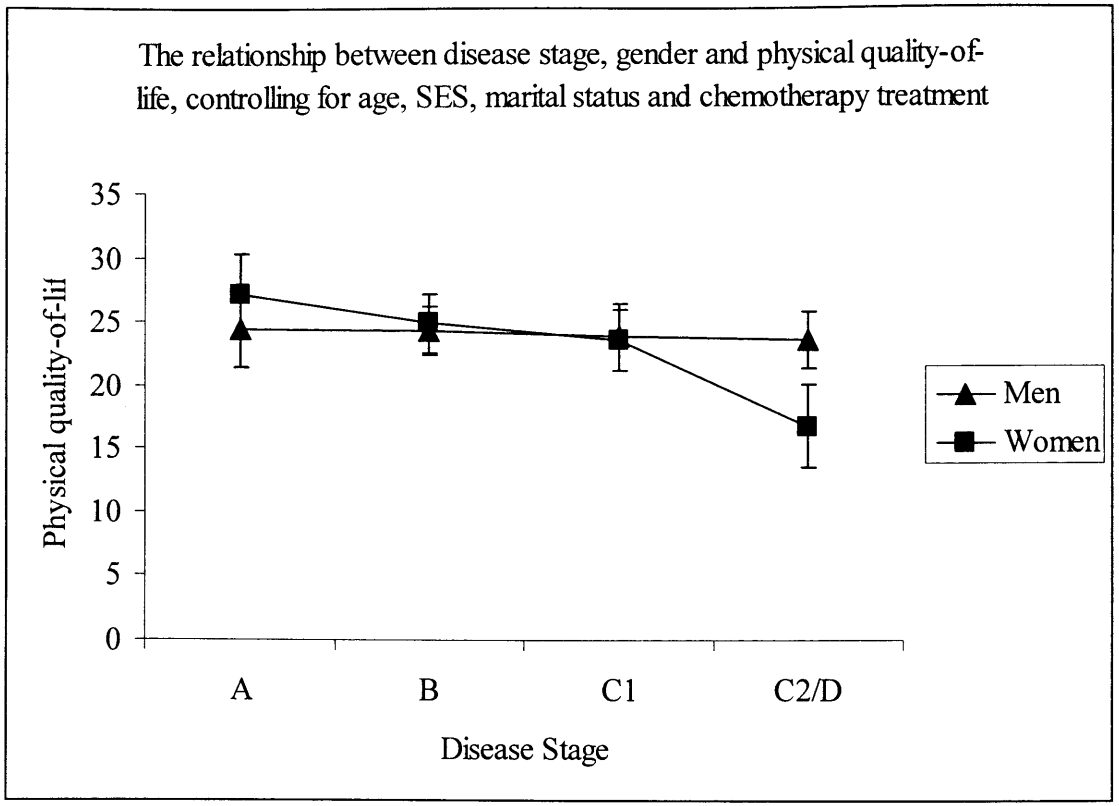
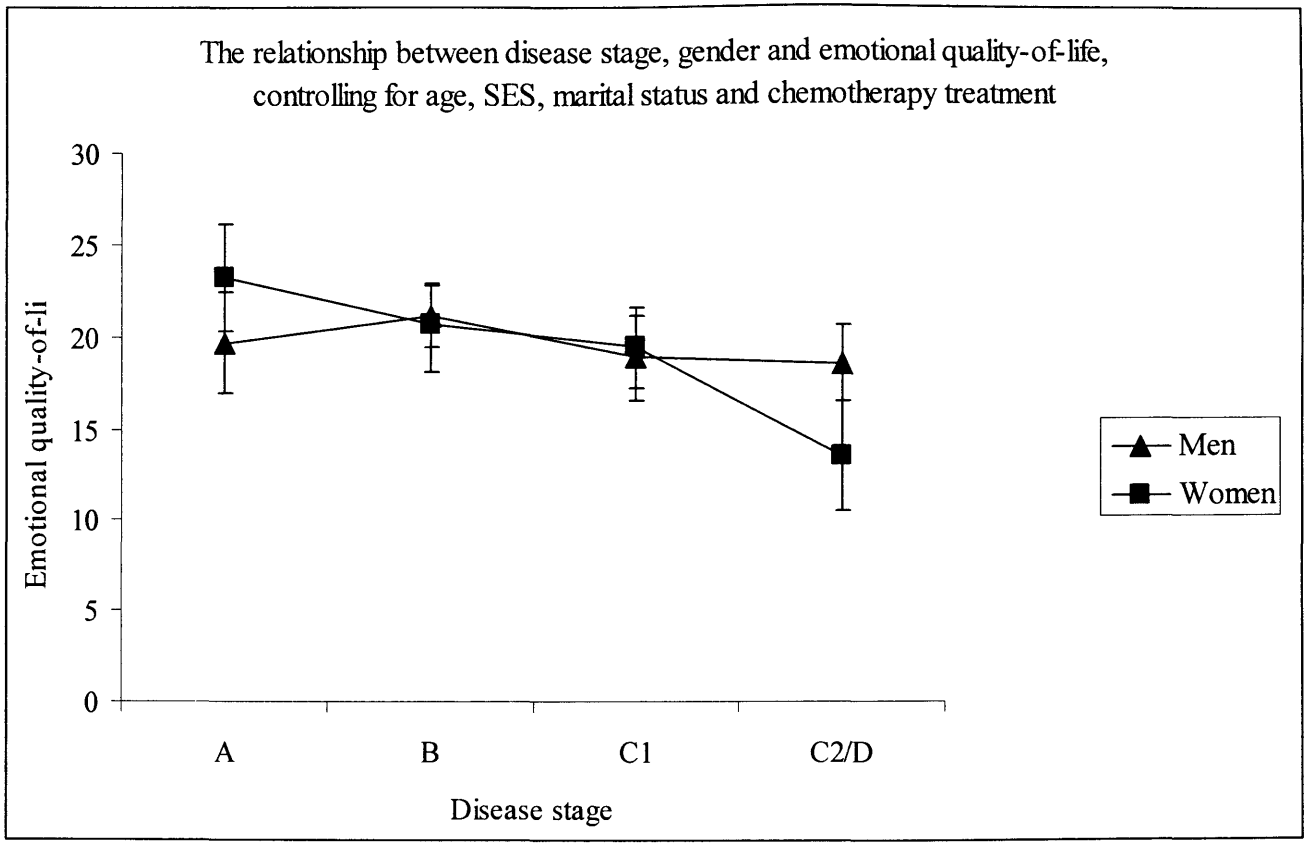

The relationship between disease stage, gender and physical quality-of-life, controlling for age, SES, marital status and chemotherapy treatment
Physical quality-of-lif
35
30
25
20
15
10
5
0
A
B
C1
C2/D
Disease Stage
Men
Women

Figure 3


The relationship between disease stage, gender and emotional quality-of-life, controlling for age, SES, marital status and chemotherapy treatment
Emotional quality-of-li
30
25
20
15
10
5
0
A
B
C1
C2/D
Disease stage
Men
Women

Appendix VII Questionnaire used in Study 2

Patient Identification Number: Centre Number: C Study Number: 1	CONFIDENTIAL

Experiences of People With Colorectal Cancer

The aim of this research is to find out more about how you have coped after your diagnosis of cancer.

- You can find more information about this study on the Patient Information Sheet.
- Some questions appear to have been repeated, but they do differ in small ways, so we would appreciate it if you could answer them all.
- Your answers will be treated in strict confidence and will help us to identify ways in which people require help with this illness.

If you are willing to be involved, please fill in this questionnaire and return it in the freepost envelope.

We are very grateful for your help with this research.

If you have any questions please contact:

Alice Simon
Cancer Research UK Health Behaviour Unit
Department of Epidemiology and Public Health
University College London

Tel:

	Male	Female
Are you male or female?	❒	❒

How old are you? ☐☐ Years

THIS SECTION ASKS ABOUT YOUR GENERAL HEALTH AND WELL-BEING.

Please circle 1 number per line to indicate how true each statement has been for you during the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4
I am able to work	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4

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	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4
I worry about dying	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ *and go to the next question*					
I am satisfied with my sex life	0	1	2	3	4

Please read each question carefully and tick the response that best describes your answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty in maintaining your independence?	☐	☐	☐	☐
Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	☐	☐	☐	☐
Have you had any difficulty with managing your own personal care?	☐	☐	☐	☐
Have you had any difficulty with looking after those who depend on you? e.g. children, dependent adults, pets)	☐	☐	☐	☐
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	☐	☐	☐	☐

THESE STATEMENTS ARE ABOUT YOUR EXPERIENCES WITH YOUR MEDICAL TEAM

Please read each statement and **circle one number** that best describes how much each statement applies to you **during the past month**, including today.

	Not at all	A little	A fair amount	Much	Very much
I find that the medical team withholds information from me about the cancer	0	1	2	3	4
I find that doctors don't explain what they are doing to me	0	1	2	3	4
I have difficulty asking doctors questions	0	1	2	3	4
I have difficulty expressing my feelings to the doctors and nurses	0	1	2	3	4
I have difficulty understanding what the doctors tell me about the cancer or its treatments	0	1	2	3	4
I would like to have more control over what the doctors do to me	0	1	2	3	4

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THIS ASKS ABOUT OUT HOW YOUR ILLNESS HAS AFFECTED YOU FINANCIALLY AND AT WORK

At what age did you leave full-time education? ☐☐

What is the highest level of educational or professional qualification you have obtained?

- ☐ GCSE/ School certificate/ O-level/CSE
- ☐ Vocational qualifications (e.g. NVQ1+2)
- ☐ A-level/Higher school certificate or equivalent (e.g. NVQ3)
- ☐ Bachelor Degree or equivalent (e.g. NVQ4)
- ☐ Masters/PhD/PGCE or equivalent
- ☐ Other (Specify.....)
- ☐ No formal qualifications
- ☐ Still studying

Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	☐	☐	☐	☐
Have you had any financial difficulties?	☐	☐	☐	☐
Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	☐	☐	☐	☐
Have you had any difficulty with your work? (or education if you are a student)	☐	☐	☐	☐
Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	☐	☐	☐	☐

Are you currently:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Full-time homemaker
- ☐ Retired
- ☐ Student
- ☐ Disabled or too ill to work

If you are working, what is the full title of your main job? .....

Have you worked during the past month? **Yes** ☐ **No** ☐

Please read each statement and **circle one number** that best describes how much each statement applied to you **during the past month**, including today.

	Have not worked in the past month	Not at all	A little	A fair amount	Much	Very much
I have difficulty talking to the people who work with me about the cancer.		0	1	2	3	4
I have difficulty telling my employer that I cannot do something because of my illness.		0	1	2	3	4
I have difficulty asking for time off from work for medical treatments.		0	1	2	3	4
I have difficulty talking to my boss about the cancer		0	1	2	3	4
I am worried about being fired.		0	1	2	3	4

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Think about your family's income, which category would describe the total annual household income? (including your own and partner's salary and any benefits)

Less than £10,000 a year	£10,000-20,000 a year	£20,000-30,000 a year	£30,000-40,000 a year	£40,000-£50,000 a year	£50,000-60,000 a year	£60,000-70,000 a year	More than £70,000 a year
☐	☐	☐	☐	☐	☐	☐	☐

THE FOLLOWING SECTION ASKS ABOUT YOUR MOOD AND GENERAL OUTLOOK ON LIFE

Tick the box which best describes how often you felt or behaved this way in **the past week.**	Rarely, none of the time (less than one day)	Some or little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4days)	Most or all of the time (5-7 days)
I was bothered by things that don't usually bother me.	☐	☐	☐	☐
I did not feel like eating; my appetite was poor.	☐	☐	☐	☐
I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
I felt depressed.	☐	☐	☐	☐
I felt that everything I did was an effort.	☐	☐	☐	☐
I felt hopeful about the future	☐	☐	☐	☐
I thought my life had been a failure.	☐	☐	☐	☐
I felt tearful.	☐	☐	☐	☐
My sleep was restless.	☐	☐	☐	☐
I was happy.	☐	☐	☐	☐
I talked less than usual.	☐	☐	☐	☐
I felt lonely.	☐	☐	☐	☐
People were unfriendly.	☐	☐	☐	☐
I enjoyed life.	☐	☐	☐	☐
I had crying spells.	☐	☐	☐	☐
I felt sad.	☐	☐	☐	☐
I felt that people disliked me.	☐	☐	☐	☐
I could not get 'going'.	☐	☐	☐	☐

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Please mark one box for each statement to show how you have usually felt over the past week:				
Worrying thoughts go through my mind:	A great deal of the time ☐	A lot of the time ☐	From time to time but not too often ☐	Only occasionally ☐
I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly ☐	Yes, but not too badly ☐	A little, but it doesn't worry me ☐	Not at all ☐
I feel restless as if I have to be on the move:	Very much indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I get sudden feelings of panic:	Very often indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I can sit at ease and feel relaxed:	Definitely ☐	Usually ☐	Not often ☐	Not at all ☐
I get a sort of frightened feeling like 'butterflies' in the stomach:	Very often ☐	Quite often ☐	Occasionally ☐	Not at all ☐
I feel tense or wound up:	Most of the time ☐	A lot of the time ☐	From time to time, occasionally ☐	Not at all ☐

PEOPLE WITH CANCER SOMETIMES FEEL THAT HAVING CANCER MAKES POSITIVE CONTRIBUTIONS TO THEIR LIVES, AS WELL AS CAUSING PROBLEMS. IS THIS TRUE FOR YOU?

Indicate how much you agree with each of the following, using these response options.					
Having had cancer ...	Not at all	A Little	Moderately	Quite a bit	Extremely
has led me to be more accepting of things.	☐	☐	☐	☐	☐
has taught me how to adjust to things I cannot change.	☐	☐	☐	☐	☐
has helped me take things as they come.	☐	☐	☐	☐	☐
has taught me that everyone has a purpose in life.	☐	☐	☐	☐	☐
has shown me that all people need to be loved.	☐	☐	☐	☐	☐
has made me more aware and concerned for the future of all human beings.	☐	☐	☐	☐	☐
has taught me to be patient.	☐	☐	☐	☐	☐
has led me to deal better with stress and problems.	☐	☐	☐	☐	☐
has contributed to my overall emotional and spiritual growth.	☐	☐	☐	☐	☐
has helped me become more focused on priorities, with a deeper sense of purpose in life	☐	☐	☐	☐	☐
has helped me become a stronger person, more able to cope effectively with future life challenges.	☐	☐	☐	☐	☐

THESE ARE QUESTIONS ABOUT DIFFERENT WAYS OF COPING WITH YOUR ILLNESS

There are many ways to deal with problems, people deal with things in different ways, please try to think about what you have been doing. Tick one box for each item and make your answers as true for you as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	☐	☐	☐	☐
I've been concentrating my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
I've been saying to myself "this isn't real".	☐	☐	☐	☐
I've been using alcohol or other drugs to make me feel better.	☐	☐	☐	☐
I've been giving up trying to deal with it.	☐	☐	☐	☐
I've been taking action to try to make the situation better.	☐	☐	☐	☐
I've been refusing to believe that it has happened.	☐	☐	☐	☐
I've been saying things to let my unpleasant feelings escape.	☐	☐	☐	☐
I've been blaming myself for things that happened.	☐	☐	☐	☐
I've been trying to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
I've been criticising myself.	☐	☐	☐	☐
I've been trying to come up with a strategy about what to do.	☐	☐	☐	☐
I've been giving up the attempt to cope.	☐	☐	☐	☐
I've been looking for something good in what is happening.	☐	☐	☐	☐
I've been making jokes about it.	☐	☐	☐	☐
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.	☐	☐	☐	☐
I've been accepting the reality of the fact that it has happened.	☐	☐	☐	☐
I've been expressing my negative feelings.	☐	☐	☐	☐
I've been praying or meditating.	☐	☐	☐	☐
I've been trying to find comfort in my religion and spiritual beliefs.	☐	☐	☐	☐
I've been learning to live with it.	☐	☐	☐	☐
I've been thinking hard about what steps to take.	☐	☐	☐	☐
I've been using alcohol or drugs to help me get through it.	☐	☐	☐	☐
I've been making fun of the situation.	☐	☐	☐	☐

SOME QUESTIONS ABOUT YOU AND YOUR FAMILY

What is your marital status?

Married/Living with partner	Single	Divorced	Separated	Widowed
☐	☐	☐	☐	☐

How many children do you have?

None	1	2	3	More than 3
☐	☐	☐	☐	☐

How many people live in your household? ☐☐

Please tick the box which best describes your living arrangement:

Rent from local authority	Rent from private landlord	Own/buying own home	Live with parents/family	Other
☐	☐	☐	☐	☐

	No	Yes, one	Yes, More than one
Does your household have a car or van?	☐	☐	☐

	Yes	No
Do you have access to the internet?	☐	☐
Have you used the Internet to find out more about your disease?	☐	☐

IF you use the Internet, how often do you usually use it?	Once or more a day	Several times a week	About once a week	About 2-3 times a month	Once a month or less
	☐	☐	☐	☐	☐

These statements deal with **discussion of your disease with your partner and/or your children.** Please indicate for every statement whether you agree or disagree with it.

	Strongly agree	Agree	Disagree	Strongly disagree
I talk as little as possible about my illness because I don't want to make my family uneasy.	☐	☐	☐	☐
If I talk about my illness, others gloss over it.	☐	☐	☐	☐
My family always wants to hear from me that I am doing well.	☐	☐	☐	☐
Talking about my emotions related to my illness upsets my family.	☐	☐	☐	☐
I am mostly the one who starts a conversation in the family about my disease.	☐	☐	☐	☐

If you do not have a partner or children please tick the 'NA' box for these statements.

	Strongly agree	Agree	Disagree	Strongly disagree	NA
My partner doesn't like me to talk about my problems.	☐	☐	☐	☐	☐
My partner often doesn't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐
My children don't like me to talk about my problems.	☐	☐	☐	☐	☐
My children often don't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐

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Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty with communicating with those close to you? (e.g. partner, children, parents)	☐	☐	☐	☐
Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	☐	☐	☐	☐
Have you had any difficulty concerning sexual matters?	☐	☐	☐	☐
Have you had any difficulty concerning plans to have a family?	☐	☐	☐	☐
Have you had any difficulty concerning your appearance or body image?	☐	☐	☐	☐
Have you felt isolated?	☐	☐	☐	☐

THIS SECTION ASKS ABOUT THE SUPPORT YOU RECEIVE FROM THE OTHER PEOPLE

Please circle one response to indicate how much you agree with each statement.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
There is a special person who is around when I am in need.	1	2	3	4	5
There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
My family really tries to help me.	1	2	3	4	5
I get the emotional help and support I need from my family.	1	2	3	4	5
I have a special person who is a real source of comfort to me.	1	2	3	4	5
My friends really try to help me.	1	2	3	4	5
I can count on my friends when things go wrong.	1	2	3	4	5
I can talk about my problems with my family.	1	2	3	4	5
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
There is a special person in my life who cares about my feelings.	1	2	3	4	5
My family is willing to help me make decisions.	1	2	3	4	5
I can talk about my problems with my friends.	1	2	3	4	5

HAVE YOU HAD ANY EVERYDAY DIFFICULTIES FOLLOWING YOUR DIAGNOSIS?

Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	☐	☐	☐	☐
Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	☐	☐	☐	☐
Have you had any difficulty in carrying out our recreational activities? (e.g. hobbies, pastimes, social pursuits)	☐	☐	☐	☐
Have you had any difficulty with your plans to travel or take a holiday?	☐	☐	☐	☐
Have you had any difficulty with any other area of your everyday life?	☐	☐	☐	☐

THESE QUESTIONS ARE ABOUT SYMPTOMS ASSOCIATED WITH COLORECTAL CANCER

Please circle 1 number per line to indicate how true each statement has been for you during the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have swelling or cramps in my stomach area	0	1	2	3	4
I am losing weight	0	1	2	3	4
I have control of my bowels	0	1	2	3	4
I can digest food well	0	1	2	3	4
I have diarrhoea	0	1	2	3	4
I have a good appetite	0	1	2	3	4
I like the appearance of my body	0	1	2	3	4
Do you have an ostomy appliance?	☐ No		☐ Yes		
If yes, please answer the next two items:					
I am embarrassed by my ostomy appliance	0	1	2	3	4
Caring for my ostomy appliance is difficult	0	1	2	3	4

MEDICAL INFORMATION:

On what date did you receive your cancer diagnosis? (dd/mm/yy) ☐☐/☐☐/☐☐

Have you already received any of the following treatments? (tick ALL that apply)

Surgery	Radiotherapy	Chemotherapy	Hormone therapy (e.g. Tamoxifen)	Any other treatments?
☐	☐	☐	☐	☐
				Please specify.....

Have your lymph glands have been affected by cancer?.....

What is your ethnic group? Please tick as appropriate. If you are descended from more than one ethnic group, please tick the group to which you consider that you belong, or tick 'any other ethnic group' and then describe your background in the space provided.

White	☐	Indian	☐
Black-Caribbean	☐	Pakistani	☐
Black-African	☐	Bangladeshi	☐
Black other	☐	Chinese	☐
Please specify.....		Any other ethnic group	☐
		Please specify.....	

MEDICAL CONSENT: Please read and sign below

We would like to obtain your permission for the medical team to review your notes and share some of this information with us. We will be looking for information about your diagnosis and treatment. If you are happy for us to do this, please read and sign the statement below.

I understand that setions of any of my medical notes may be looked at by responsible individuals from the Cancer Research UK Health Behaviour Unit at University College London. I give permission for these individuals to have access to my records.

Signed..... Date.....

FUTURE CONTACT?

In the future we may be carrying out more surveys like this. If you would be willing to be contacted again, **please tick this box** ☐

WE ARE VERY INTERESTED IN HEARING YOUR THOUGHTS ABOUT THIS QUESTIONNAIRE; SO PLEASE WRITE ANY COMMENTS YOU HAVE IN THE BOX BELOW:

Thank you very much for taking the time to fill in this questionnaire.

Appendix VIII – Ethical approval for Study 2

Isle of Wight, Portsmouth & SE Hants Local Research Ethics Committee

Professor J Wardle
Director
Cancer Research UK Health Behaviour Unit
Department of Epidemiology and Public Health

12 June 2003

Dear Prof Wardle

REC Prop No: **04/03/1480**
Title: **Socio-economic status and coping with cancer - examining the experiences of people diagnosed with colorectal cancer**

The Chair of the Local Research Ethics Committee has considered your response to the issues the committee raised and is satisfied your response has fulfilled their requirements. The Chair, acting under delegated authority, has therefore approved the above study. Approval for the study is only granted until the end of 31st December 2003. If your study continues after this date further Ethics Committee approval will be required.

The following documents were reviewed:

Protocol	Undated
Patient information sheet	Version 1, dated 14th April 2003
Letter to patient and reminder letter	Undated
Questionnaire	Undated
Application Form	dated 16/04/03
Data Protection Questionnaire (v2)	dated 14/04/03
Curriculum Vitae - Frances Jane Wardle	Undated
Letter of thanks to patient after questionnaire received	Undated

The Ethics Committee will require a copy of the completed study for its records, you are therefore requested to submit a copy of the completed study to the address above.

The Committee must be informed of any untoward or adverse events, which occur during the course of the study.

Please inform the Committee if the study is withdrawn, or does not take place.

The Ethics Committee must also be informed of, and approve, any proposed amendments to your initial application.

cont/...

Please note it is the policy of the Committee NOT to deal direct with sponsoring companies. All correspondence (including telephone enquiries) MUST be from the first named researcher. Enquiries from other sources will be refused.

Ethics Committee approval means that the proposal is ethically sound. It does not mean approval of resources, access to data or any other requirement relating to the project. These must be agreed with the organisation where the research / project is to take place.

If you have any further questions please do not hesitate to contact me quoting the Research Ethics Committee Proposal Number given above.

Yours sincerely

Administrator to the Research Ethics Committee

E-mail:

cc Alice Simon

NB: The Committee endorses the Royal College of Physicians Report on 'Fraud & Misconduct in Medical Research Practice 1991'. This states that all original data (eg questionnaires, lab books, hard copies of any computer data) are kept for a minimum of ten years in a retrievable form. If storage is to be outside either Portsmouth Hospitals or Portsmouth HealthCare NHS Trusts' premises, the Committee must be informed of the site of storage. It is a condition of any approval that such storage occurs.

Appendix IX – Interview Topic Guide for Study 3

Interview Topic Guide

Questions will be set within the topics listed below, however respondents will be encouraged to express any additional views which lie outside the topics specified to allow a patient-centred approach.

Interview topics:

1. Open-ended invitation to relate cancer 'story'.
2. Access to care, comprehensibility of medical information and doctor-patient relationship.
3. Coping strategies employed and their success or failure.
4. Issues surrounding social support (perceived need versus received support and effect on personal relationships).
5. Issues of disclosure of illness to family and workplace and effect on relationships.
6. Recent emotional and physical well-being
7. Social expectations and norms within family/friend groups regarding cancer and illness.
8. Issues in everyday life that have changed as result of illness, e.g. finances, social roles, employment, travel etc.

SAMPLE QUESTIONS

Open-ended invitation to relate cancer 'story'.

e.g. **Could you start by describing when you first realised that you might have cancer?**

PERSONAL WELL-BEING & BENEFIT FINDING

- Has this illness changed how you feel about yourself?
- Has this illness changed how you think about your future?
- How have you been feeling in yourself since you received your diagnosis?
- How stressful would you say it has been to have this illness?
- What sort of things do you do to cope?

STRESS & LIFESTYLE

- Has this illness had any effect on your usual lifestyle?
- Have you made changes in your life because of your illness?
- Are there other stressful things going on in your life?
- How do you balance these?
- Are there any financial implications for you that result from having cancer?
- Are you employed or retired (get info about last job if retired)? What effect has your illness had in this area of your life?
- Do you think that your experience with this illness has been different compared to other people who have a different background or lifestyle? **AND 2)** compared to people of a different age?
- Do you think that people from a different area or social background would have coped with this illness differently to you?**AND 2)** people of a different age?

MEDICAL TEAM & Information/comprehension

- What has your experience been like with the medical care at this hospital?
- Could you tell me something about the doctors and nurses that you've come across?
- Do you find it easy to understand what the doctor says?
- Do you find it easy to understand what the nurses says?
- Do you prefer speaking to nurses or doctors?
- What sources/where have you gained information about this disease from? Is it enough information? Were you able to understand it?

TRAVEL

- How easy is it for you to reach the hospital?
- Have you made any changes in how you get around since your diagnosis?
- Has it had an effect on any of your travel plans?

SOCIAL SUPPORT

- Among people you know and spend time with do you talk about cancer generally?
- If you wanted to could you talk about your own illness with these people?
- How has your family reacted to your illness?

Appendix X – Questionnaire used in Studies 3, 4, and 5

Patient Identification Number: Centre Number: B Study Number: 1	CONFIDENTIAL

Experiences of People Recently Diagnosed with Cancer

The aim of this research is to find out more about the difficulties you have had and how you have coped after your diagnosis of cancer.

- You can find more information about this study on the Patient Information Sheet.
- Some questions appear to have been repeated, but they do differ in small ways, so we would appreciate it if you could answer them all.
- Your answers will be treated in strict confidence and will help us to identify ways in which people require help with this illness.

If you are willing to be involved, please fill in this questionnaire and return it with your Consent Form and Address Sheet in the freepost envelope.

We are very grateful for your help with this research.

If you have any questions please contact:

Alice Simon
Cancer Research UK Health Behaviour Unit
Department of Epidemiology and Public Health
University College London

Tel:

How old are you? ☐☐ **Years**

THIS SECTION ASKS ABOUT YOUR GENERAL HEALTH AND WELL-BEING.

Please circle 1 number per line to indicate how true each statement has been for you during the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4
I am able to work	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I worry about dying	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ *and go to the next question*					
I am satisfied with my sex life	0	1	2	3	4

Please read each question carefully and tick the response that best describes your answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty in maintaining your independence?	☐	☐	☐	☐
Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	☐	☐	☐	☐
Have you had any difficulty with managing your own personal care?	☐	☐	☐	☐
Have you had any difficulty with looking after those who depend on you? e.g. children, dependent adults, pets)	☐	☐	☐	☐
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	☐	☐	☐	☐

THESE STATEMENTS ARE ABOUT YOUR EXPERIENCES WITH YOUR MEDICAL TEAM

Please read each statement and **circle one number** that best describes how much each statement applies to you **during the past month**, including today.

	Not at all	A little	A fair amount	Much	Very much
I find that the medical team withholds information from me about the cancer	0	1	2	3	4
I find that doctors don't explain what they are doing to me	0	1	2	3	4
I have difficulty asking doctors questions	0	1	2	3	4
I have difficulty expressing my feelings to the doctors and nurses	0	1	2	3	4
I have difficulty understanding what the doctors tell me about the cancer or its treatments	0	1	2	3	4
I would like to have more control over what the doctors do to me	0	1	2	3	4

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THIS ASKS ABOUT OUT HOW YOUR ILLNESS HAS AFFECTED YOU FINANCIALLY AND AT WORK

At what age did you leave full-time education? ☐☐

What is the highest level of educational or professional qualification you have obtained?

- ☐ GCSE/ School certificate/ O-level/CSE
- ☐ Vocational qualifications (e.g. NVQ1+2)
- ☐ A-level/Higher school certificate or equivalent (e.g. NVQ3)
- ☐ Bachelor Degree or equivalent (e.g. NVQ4)
- ☐ Masters/PhD/PGCE or equivalent
- ☐ Other (Specify.....)
- ☐ No formal qualifications
- ☐ Still studying

Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	☐	☐	☐	☐
Have you had any financial difficulties?	☐	☐	☐	☐
Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	☐	☐	☐	☐
Have you had any difficulty with your work? (or education if you are a student)	☐	☐	☐	☐
Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	☐	☐	☐	☐

Are you currently:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Full-time homemaker
- ☐ Retired
- ☐ Student
- ☐ Disabled or too ill to work

If you are working, what is the full title of your main job? .....

Have you worked during the past month? **Yes** ☐ **No** ☐

Please read each statement and **circle one number** that best describes how much each statement applied to you **during the past month**, including today.

	Have not worked in the past month	Not at all	A little	A fair amount	Much	Very much
I have difficulty talking to the people who work with me about the cancer.	☐	0	1	2	3	4
I have difficulty telling my employer that I cannot do something because of my illness.	☐	0	1	2	3	4
I have difficulty asking for time off from work for medical treatments.	☐	0	1	2	3	4
I have difficulty talking to my boss about the cancer	☐	0	1	2	3	4
I am worried about being fired.	☐	0	1	2	3	4

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Think about your family's income, which category would describe the total annual household income? (including your own and partner's salary and any benefits)

Less than £10,000 a year	£10,000-20,000 a year	£20,000-30,000 a year	£30,000-40,000 a year	£40,000-£50,000 a year	£50,000-60,000 a year	£60,000-70,000 a year	More than £70,000 a year
☐	☐	☐	☐	☐	☐	☐	☐

THE FOLLOWING SECTION ASKS ABOUT HOW YOU HAVE BEEN FEELING RECENTLY

Tick the box which best describes how often you felt or behaved this way in **the past week**.

	Rarely, none of the time (less than one day)	Some or little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4days)	Most or all of the time (5-7 days)
I was bothered by things that don't usually bother me.	☐	☐	☐	☐
I did not feel like eating: my appetite was poor.	☐	☐	☐	☐
I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
I felt depressed.	☐	☐	☐	☐
I felt that everything I did was an effort.	☐	☐	☐	☐
I felt hopeful about the future	☐	☐	☐	☐
I thought my life had been a failure.	☐	☐	☐	☐
I felt tearful.	☐	☐	☐	☐
My sleep was restless.	☐	☐	☐	☐
I was happy.	☐	☐	☐	☐
I talked less than usual.	☐	☐	☐	☐
I felt lonely.	☐	☐	☐	☐
People were unfriendly.	☐	☐	☐	☐
I enjoyed life.	☐	☐	☐	☐
I had crying spells.	☐	☐	☐	☐
I felt sad.	☐	☐	☐	☐
I felt that people disliked me.	☐	☐	☐	☐
I could not get 'going'.	☐	☐	☐	☐

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Please mark one box for each statement to show how you have usually felt over the past week:				
Worrying thoughts go through my mind:	A great deal of the time ☐	A lot of the time ☐	From time to time but not too often ☐	Only occasionally ☐
I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly ☐	Yes, but not too badly ☐	A little, but it doesn't worry me ☐	Not at all ☐
I feel restless as if I have to be on the move:	Very much indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I get sudden feelings of panic:	Very often indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I can sit at ease and feel relaxed:	Definitely ☐	Usually ☐	Not often ☐	Not at all ☐
I get a sort of frightened feeling like 'butterflies' in the stomach:	Very often ☐	Quite often ☐	Occasionally ☐	Not at all ☐
I feel tense or wound up:	Most of the time ☐	A lot of the time ☐	From time to time, occasionally ☐	Not at all ☐

Please answer according to your own feelings and **how you <u>generally</u> feel**, rather than how you think 'most people' would answer. Please tick one box for each statement.

	I agree a lot	I agree a little	I neither agree nor disagree	I disagree a little	I disagree a lot
I'm always optimistic about my future.	☐	☐	☐	☐	☐
I hardly ever expect things to go my way.	☐	☐	☐	☐	☐
In uncertain times, I usually expect the best.	☐	☐	☐	☐	☐
If something can go wrong for me, it will.	☐	☐	☐	☐	☐
I rarely count on good things happening to me.	☐	☐	☐	☐	☐
Overall, I expect more good things to happen to me than bad.	☐	☐	☐	☐	☐
I have little control over the things that happen to me	☐	☐	☐	☐	☐
There is really no way I can solve some of the problems I have	☐	☐	☐	☐	☐
There is little I can do to change many of the important things in my life	☐	☐	☐	☐	☐
I often feel helpless in dealing with the problems of life	☐	☐	☐	☐	☐
Sometimes I feel that I'm being pushed around in life	☐	☐	☐	☐	☐
What happens to me in the future mostly depends on me	☐	☐	☐	☐	☐
I can do just about anything I really set my mind to do	☐	☐	☐	☐	☐

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NEXT, SOME QUESTIONS ABOUT THE WAY YOU THINK AND FEEL ABOUT HAVING CANCER

These questions ask about how you think and feel about having cancer. Please circle the number that best describes your response:

	Not at all		Somewhat				Definitely yes
Would you describe this illness as harmful?	0	1	2	3	4	5	6
Would you describe this illness as threatening?	0	1	2	3	4	5	6
Would you describe this illness as a loss?	0	1	2	3	4	5	6
Would you describe this illness as a challenge?	0	1	2	3	4	5	6
Would you rate the experience of this illness as stressful or worrying?	0	1	2	3	4	5	6
Do you feel you have the energy and stamina to get through this?	0	1	2	3	4	5	6
Are you pleased with your outlook on things?	0	1	2	3	4	5	6
Are you pleased with the way you are handling things?	0	1	2	3	4	5	6

PEOPLE WITH CANCER SOMETIMES FEEL THAT HAVING CANCER MAKES POSITIVE CONTRIBUTIONS TO THEIR LIVES, AS WELL AS CAUSING PROBLEMS, IS THIS TRUE FOR YOU?

Indicate how much you agree with each of the following, using these response options.

Having had cancer ...	Not at all	A Little	Moderately	Quite a bit	Extremely
has led me to be more accepting of things.	☐	☐	☐	☐	☐
has taught me how to adjust to things I cannot change.	☐	☐	☐	☐	☐
has helped me take things as they come.	☐	☐	☐	☐	☐
has taught me that everyone has a purpose in life.	☐	☐	☐	☐	☐
has shown me that all people need to be loved.	☐	☐	☐	☐	☐
has made me more aware and concerned for the future of all human beings.	☐	☐	☐	☐	☐
has taught me to be patient.	☐	☐	☐	☐	☐
has led me to deal better with stress and problems.	☐	☐	☐	☐	☐
has contributed to my overall emotional and spiritual growth.	☐	☐	☐	☐	☐
has helped me become more focused on priorities, with a deeper sense of purpose in life	☐	☐	☐	☐	☐
has helped me become a stronger person, more able to cope effectively with future life challenges.	☐	☐	☐	☐	☐

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THESE ARE QUESTIONS ABOUT DIFFERENT WAYS OF COPING WITH YOUR ILLNESS

There are many ways to deal with problems, people deal with things in different ways, please try to think about what you have been doing. Tick one box for each item and make your answers as true for you as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	☐	☐	☐	☐
I've been concentrating my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
I've been saying to myself "this isn't real".	☐	☐	☐	☐
I've been using alcohol or other drugs to make me feel better.	☐	☐	☐	☐
I've been giving up trying to deal with it.	☐	☐	☐	☐
I've been taking action to try to make the situation better.	☐	☐	☐	☐
I've been refusing to believe that it has happened.	☐	☐	☐	☐
I've been saying things to let my unpleasant feelings escape.	☐	☐	☐	☐
I've been blaming myself for things that happened.	☐	☐	☐	☐
I've been trying to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
I've been criticising myself.	☐	☐	☐	☐
I've been trying to come up with a strategy about what to do.	☐	☐	☐	☐
I've been giving up the attempt to cope.	☐	☐	☐	☐
I've been looking for something good in what is happening.	☐	☐	☐	☐
I've been making jokes about it.	☐	☐	☐	☐
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.	☐	☐	☐	☐
I've been accepting the reality of the fact that it has happened.	☐	☐	☐	☐
I've been expressing my negative feelings.	☐	☐	☐	☐
I've been praying or meditating.	☐	☐	☐	☐
I've been trying to find comfort in my religion and spiritual beliefs.	☐	☐	☐	☐
I've been learning to live with it.	☐	☐	☐	☐
I've been thinking hard about what steps to take.	☐	☐	☐	☐
I've been using alcohol or drugs to help me get through it.	☐	☐	☐	☐
I've been making fun of the situation.	☐	☐	☐	☐

SOME QUESTIONS ABOUT YOU AND YOUR FAMILY

What is your marital status?

Married/Living with partner	Single	Divorced	Separated	Widowed
☐	☐	☐	☐	☐

How many children do you have?

None	1	2	3	More than 3
☐	☐	☐	☐	☐

How many people live in your household? ☐☐

Please tick the box which best describes your living arrangement:

Rent from local authority	Rent from private landlord	Own/buying own home	Live with parents/family	Other
☐	☐	☐	☐	☐

Does your household have a car or van?	No	Yes, one	Yes, More than one
	☐	☐	☐

	Yes	No
Do you have access to the internet?	☐	☐
Have you used the Internet to find out more about your disease?	☐	☐

IF you use the internet, how often do you usually use it?	Once or more a day	Several times a week	About once a week	About 2-3 times a month	Once a month or less
	☐	☐	☐	☐	☐

These statements deal with **discussion of your disease with your partner and/or your children.** Please indicate for every statement whether you agree or disagree with it.

	Strongly agree	Agree	Disagree	Strongly disagree
I talk as little as possible about my illness because I don't want to make my family uneasy.	☐	☐	☐	☐
If I talk about my illness, others gloss over it.	☐	☐	☐	☐
My family always wants to hear from me that I am doing well.	☐	☐	☐	☐
Talking about my emotions related to my illness upsets my family.	☐	☐	☐	☐
I am mostly the one who starts a conversation in the family about my disease.	☐	☐	☐	☐

If you do not have a partner or children please tick the 'NA' box for these statements.

	Strongly agree	Agree	Disagree	Strongly disagree	NA
My partner doesn't like me to talk about my problems.	☐	☐	☐	☐	☐
My partner often doesn't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐
My children don't like me to talk about my problems.	☐	☐	☐	☐	☐
My children often don't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐

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Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty with communicating with those close to you? (e.g. partner, children, parents)	☐	☐	☐	☐
Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	☐	☐	☐	☐
Have you had any difficulty concerning sexual matters?	☐	☐	☐	☐
Have you had any difficulty concerning plans to have a family?	☐	☐	☐	☐
Have you had any difficulty concerning your appearance or body image?	☐	☐	☐	☐
Have you felt isolated?	☐	☐	☐	☐

THIS SECTION ASKS ABOUT THE SUPPORT YOU RECEIVE FROM THE OTHER PEOPLE

Please circle one response to indicate how much you agree with each statement.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
There is a special person who is around when I am in need.	1	2	3	4	5
There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
My family really tries to help me.	1	2	3	4	5
I get the emotional help and support I need from my family.	1	2	3	4	5
I have a special person who is a real source of comfort to me.	1	2	3	4	5
My friends really try to help me.	1	2	3	4	5
I can count on my friends when things go wrong.	1	2	3	4	5
I can talk about my problems with my family.	1	2	3	4	5
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
There is a special person in my life who cares about my feelings.	1	2	3	4	5
My family is willing to help me make decisions.	1	2	3	4	5
I can talk about my problems with my friends.	1	2	3	4	5

HAVE YOU HAD ANY EVERYDAY DIFFICULTIES FOLLOWING YOUR DIAGNOSIS?

Please read each question carefully and tick the response that best describes you answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	☐	☐	☐	☐
Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	☐	☐	☐	☐
Have you had any difficulty in carrying out our recreational activities? (e.g. hobbies, pastimes, social pursuits)	☐	☐	☐	☐
Have you had any difficulty with your plans to travel or take a holiday?	☐	☐	☐	☐
Have you had any difficulty with any other area of your everyday life?	☐	☐	☐	☐

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THESE QUESTIONS ARE ABOUT SYMPTOMS AND CONCERNS ASSOCIATED WITH BREAST CANCER

Please circle 1 number per line to indicate how true each statement has been for you during the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have been short of breath	0	1	2	3	4
I am self-conscious about the way I dress	0	1	2	3	4
One or both of my arms are swollen or tender	0	1	2	3	4
I feel sexually attractive	0	1	2	3	4
I am bothered by hair loss	0	1	2	3	4
I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
I worry about the effect of stress on my illness	0	1	2	3	4
I am bothered by a change in weight	0	1	2	3	4
I am able to feel like a woman	0	1	2	3	4
I have certain parts of my body where I experience significant pain	0	1	2	3	4

MEDICAL INFORMATION:

On what date did you receive your cancer diagnosis? (dd/mm/yy) ☐☐/☐☐/☐☐

Have you already received any of the following treatments? (tick ALL that apply)

Surgery	Radiotherapy	Chemotherapy	Hormone therapy (e.g. Tamoxifen)	Any other treatments?
☐	☐	☐	☐	☐
				Please specify.....

Have your lymph glands been affected by cancer?.....

What is your ethnic group? Please tick as appropriate. If you are descended from more than one ethnic group, please tick the group to which you consider that you belong, or tick 'any other ethnic group' and then describe your background in the space provided.

White	☐	Indian	☐
Black-Caribbean	☐	Pakistani	☐
Black-African	☐	Bangladeshi	☐
Black other	☐	Chinese	☐
Please specify.....		Any other ethnic group	☐
		Please specify.....	

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WE ARE VERY INTERESTED IN HEARING YOUR THOUGHTS ABOUT THIS QUESTIONNAIRE: SO PLEASE WRITE ANY COMMENTS YOU HAVE IN THE BOX BELOW:

Thank you very much for taking the time to fill in this questionnaire.

Appendix XI – Ethical Approval for Studies 3, 4, 5 and 6

NHS

The London Multi-Centre Research Ethics Committee

7th August 2002
pw/lc/02-61

Professor Jane Wardle
Director of CRUK Health Behaviour Unit
Department of Epidemiology & Public Health
University College London

Dear Professor Wardle

Application Reference Number **MREC/02/2/61**
Title **Socio-economic status and coping with cancer – examining the experiences of people recently diagnosed with cancer**

The Chairman of the London Multicentre Research Ethics Committee has considered the amendments submitted in response to the Committee's earlier review of your application on 26th June 2002 as set out in our letter dated 5th July 2002. The documents considered were as follows:

Letter from Professor Wardle	*(dated 15th July 2002)*
MREC Application Form	*(dated 28th May 2002)*
Protocol	*(Version 1, dated 15th May 2002)*
Patient Information Sheet	*(Version 2, dated 10th July 2002)*
List of Cancer Support Services	*(Version 1, dated 10th July 2002)*
Consent Form	*(Version 1, dated 15th May 2002)*
Questionnaire	*(Version 1, dated 15th May 2002)*
Interview Topic Guide	*(Version 1, dated 15th May 2002)*
Principle Researcher's Curriculum Vitae	

The Chairman, acting under delegated authority, is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of the approval set out below. A full record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

While undertaking the review of your application the MREC noted the research involves the establishment of a new disease or patient database for research purposes / the use of an existing database collected for previous research or other purposes with subsequent patient contact. **For this reason you are asked to read carefully the sections concerning LREC involvement and local NHS management set out below as there are specific requirement involved when undertaking such research.**

MREC Conditions of Approval

- No research procedures are undertaken until the appropriate local research ethics committees is informed of the research including the name of the local clinician involved.
- The local clinician must inform his/her NHS organisation of their co-operation in the research project.
- The protocol approved by the MREC is followed and any changes to the protocol are undertaken only after MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
- You must promptly inform the MREC of:
  (i) any changes that increase the risk to subjects and/or affect significantly the conduct of the research;
  (ii) any new information that may affect adversely the safety or welfare of the subjects or the conduct of the trial.
- You must complete and return to the MREC the annual review form that will be sent to you once a year, and the final report form when your research is completed.

LREC involvement

When undertaking the review of your project the MREC observed that there is/ limited patient contact involving the performance of a technical procedures or additional data collection as described in the MREC approved protocol/ initial contact by a local clinician for purposes of recruitment. It is felt that these tasks appear well within his/her routine professional competence and adequate facilities for such procedure are available as part of his/her normal professional practice.

For this reason you are asked to only inform the appropriate LREC of the project by sending a copy of this letter and also **giving the name and contact details of the local clinician involved and what procedures will be undertaken by this person.** If (unusually) the LREC has any reason to doubt that the local clinician is competent to carry out the tasks required, it will inform the clinician and the MREC that gave ethical approval giving full reasons.

When such tasks are performed by centrally based researchers it should be assumed that the MREC has reviewed their competence to undertake the tasks and it is not necessary to inform the LREC of the contact details but only that the research will take place.

You are not required to wait for confirmation from the LREC before starting your research.

Local NHS Management

The local clinician must inform his/her NHS organisation of their co-operation in the research project and the nature of their involvement. Care should be taken to ensure with the NHS organisation that local indemnity arrangements are adequate.

Legal and Regulatory Requirements

It remains your responsibility to ensure in the subsequent collection, storage or use of data or research sample you are not contravening the legal or regulatory requirements of any part of the UK in which the research material is collected, stored or used. If data is transferred outside the UK you should be aware of the requirements of the Data Protection Act 1998.

ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at www.corec.org.uk

Yours sincerely

Administrator
The London Multicentre Research Ethics Committee

Enc

NHS

The London Multi-Centre Research Ethics Committee

RESPONSE FORM

DETAILS OF APPLICANT:

1. **Name and address of Principal Researcher:**

   Professor Jane Wardle
   Director of CRUK Health Behaviour Unit
   Department of Epidemiology & Public Health
   University College London

2. **Title of Project:**

   Socio-economic status and coping with cancer – examining the experiences of people recently diagnosed with cancer

3. **Name and address of Sponsor:**

   Cancer Research UK

DETAILS OF MREC:

4. **Name and address of MREC:**

   The London Multicentre Research Ethics Committee

5. **MREC Reference Number:**

Listed below is a complete record of the review undertaken by the MREC with the decisions made, dates of decisions and the requirements at each stage of the review:

The London Multicentre Research Ethics Committee at its meeting on Wednesday 26th June 2002 approved the study subject to the following:

a) *Could the researcher clarify what support would be available should a patient become distressed during an interview? Would patients be referred to a counsellor or psychologist?*

b) *Could the researcher clarify what training would the interviewer receive?*

c) *Could the researcher provide patients with details of cancer support groups?*

d) *Could a maximum time limit be set on the interviews (for example, one hour), to prevent patients from becoming tired?*

e) *It was noted that the sample size is based on a medium size effect of 0.25. Could the researcher explain the meaning of 0.25? Could the researcher explain how this is recognised as clinically significant by those working in this field?*

f) *Could the researchers explain why the first sage of the survey is not stratified by social class, given that it is important to obtain a similar sample size in each group to optimise the efficiency of the study?*

g) *Could the researcher clarify what definitions would be used to identify the three social classes?*

h) *Does the researcher feel that by excluding patients for whom English is not a first language, the research will miss important cultural factors?*

i) *Could the researcher confirm if the questionnaire has been validated?*

The Committee delegated authority to the Chairman to approve the study, if the responses to the above were satisfactory.

Professor Wardle responded on 15th July 2002.

THE FINAL DOCUMENTS AND ARRANGEMENTS APPROVED BY THE MREC

The London Multicentre Research Ethics Committee has approved the following items:

Letter from Professor Wardle	*(dated 15th July 2002)*
MREC Application Form	*(dated 28th May 2002)*
Protocol	*(Version 1, dated 15th May 2002)*
Patient Information Sheet	*(Version 2, dated 10th July 2002)*
List of Cancer Support Services	*(Version 1, dated 10th July 2002)*
Consent Form	*(Version 1, dated 15th May 2002)*
Questionnaire	*(Version 1, dated 15th May 2002)*
Interview Topic Guide	*(Version 1, dated 15th May 2002)*
Methods of Initial Recruitment to Study	

Date of approval: 29th July 2002

Signature of Administrator: Date: 7th August 2002

Name (please print)

List of Members in Attendance at the Meeting on 26th June 2002

(Chairman)	Lay Member, Retired Engineer
	General Practitioner
	Psychologist
	Nurse
	Statistician
	Clinical Scientist
	Pharmacist
	Consultant Paediatrician
	Lay Member, Editor
	Qualitative Researcher
	Consultant Haematologist

Administrator

Appendix XII Codebook used in Study 3

Content analysis code book

ID Number.....

1. Quality of medical care/satisfaction with care

Medical care		Yes	No		Personality	Expertise	Explicit	System	General
Drs specialist	Positive	☐	☐		☐	☐	☐	☐	☐
	Negative	☐	☐		☐	☐	☐	☐	☐
Nurses specialist	Positive	☐	☐		☐	☐	☐	☐	☐
	Negative	☐	☐		☐	☐	☐	☐	☐
Dr other	Positive	☐	☐		☐	☐	☐	☐	☐
	Negative	☐	☐		☐	☐	☐	☐	☐
Nurse other	Positive	☐	☐		☐	☐	☐	☐	☐
	Negative	☐	☐		☐	☐	☐	☐	☐
GP	Positive	☐	☐		☐	☐	☐	☐	☐
	Negative	☐	☐		☐	☐	☐	☐	☐

2. Administration difficulties

Administration		
Appointments	Difficulties ☐	No difficulties ☐
Bed availability	Difficulties ☐	No difficulties ☐
Scans/medical procedures	Difficulties ☐	No difficulties ☐
Short-staffed	Difficulties ☐	No difficulties ☐
Agency nurses	Difficulties ☐	No difficulties ☐
Other administration.....	Difficulties ☐	No difficulties ☐

3. Treatments, side effects and medical history

Time to diagnosis (after referral from GP)	.....		
Diagnostic tests	Received	Planned	Not having
Flexible sigmoidoscopy	☐	☐	☐
Colonoscopy	☐	☐	☐
CT scan	☐	☐	☐
Barium enema	☐	☐	☐
Pathology	☐	☐	☐
Endoscopy (other)	☐	☐	☐
MRI scan	☐	☐	☐
Other test.....	☐	☐	☐
Treatments	Received	Planned	Not having
Surgery	☐	☐	☐
Chemotherapy	☐	☐	☐
Radiotherapy	☐	☐	☐
Other.....	☐	☐	☐
.....	.....		

Satisfaction with treatment		Yes ☐	No ☐
Side effects			
Incontinence		Yes ☐	No ☐
Hospital infection		Yes ☐	No ☐
Sexual problems		Yes ☐	No ☐
Weight loss		Yes ☐	No ☐
Painful arms/veins due to chemo		Yes ☐	No ☐
Fatigue		Yes ☐	No ☐
Loss of appetite		Yes ☐	No ☐
Other.....		Yes ☐	No ☐
Co-morbid health problems		Yes ☐	No ☐
Details.....			
Stage of disease	A ☐	B ☐	C1 ☐ C2 ☐
Colostomy	Yes ☐	No ☐	
If 'yes'	Temporary ☐	Permanent ☐	
Embarassment/difficulties with colostomy	Yes ☐	No ☐	
Symptoms prior to diagnosis	Yes ☐	No ☐	
Delay in seeking medical care regarding symptoms	Yes ☐	No ☐	
If 'yes'	Up to 1 wk ☐	Up to 2 wk ☐	Up to 1mth ☐
	Up to 3mth ☐	Up to 12mth ☐	

Appendix XIII – Questionnaire used in Study 6

Patient Identification Number:	CONFIDENTIAL
Centre Number: B	
Study Number: 2	

Experiences of People Who Have had a Diagnosis of Cancer

A few months ago you filled in a survey for us. Thank you very much for taking part.

We are now asking you to complete a similar survey to find out if your illness has continued to affect your life and to see if your views have changed over time.

- You can find more information about this study on the Patient Information Sheet.
- Your answers will be treated in strict confidence and will help us to identify ways in which people require help with this illness.
- Some questions have been repeated but this is because we want to see if your opinions have changed compared to when you first answered these questions.

If you are willing to be involved, please fill in this questionnaire and return it in the freepost envelope.

We are very grateful for your help with this research.

If you have any questions please contact:

Alice Simon
Cancer Research UK Health Behaviour Unit
Department of Epidemiology and Public Health
University College London

THIS SECTION ASKS ABOUT YOUR GENERAL HEALTH AND WELL-BEING.

Please circle 1 number per line to indicate how true each statement has been for you **during the past 7 days**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4
I am able to work	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying the things I usually do for fun	0	1	2	3	4
I worry about dying	0	1	2	3	4
I have accepted my illness	0	1	2	3	4

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4
Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ *and go to the next question*					
I am satisfied with my sex life	0	1	2	3	4

THESE STATEMENTS ARE ABOUT YOUR EXPERIENCES WITH YOUR MEDICAL TEAM

Please read each statement and **circle one number** that best describes how much each statement applies to you **during the past month**, including today.

	Not at all	A little	A fair amount	Much	Very much
I find that the medical team withholds information from me about the cancer	0	1	2	3	4
I find that doctors don't explain what they are doing to me	0	1	2	3	4
I have difficulty asking doctors questions	0	1	2	3	4
I have difficulty expressing my feelings to the doctors and nurses	0	1	2	3	4
I have difficulty understanding what the doctors tell me about the cancer or its treatments	0	1	2	3	4
I would like to have more control over what the doctors do to me	0	1	2	3	4

THIS SECTION IS ABOUT HOW YOUR ILLNESS HAS AFFECTED YOU FINANCIALLY AND AT WORK

Are you currently:

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed
- ☐ Full-time homemaker
- ☐ Retired
- ☐ Student
- ☐ Disabled or too ill to work

What is the full title of your main job, or if you are retired or unemployed what was the full title of your last job?.....

Do (did) you work as an employee or are (were) you self-employed?

Employee ☐ Self-employed with employees ☐ Self-employed/freelance without employees ☐

For employees: Indicate how many people work (worked) for your employer 1 to 24 ☐

For self-employed: Indicate how many people you employ (employed) 25 or more ☐

Do (did) you supervise any other employees? Yes ☐ No ☐

The following questions refer to your current main job, or to your last main job. Please tick one box only.

Please tick one box to show which best describes the sort or work you do (did):

Modern professional occupations
such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer ☐

Clerical and intermediate occupations
such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse ☐

Senior managers or administrators
(usually responsible for planning, organising and co-ordinating work and for finance)
such as: finance manager - chief executive ☐

Technical and craft occupations
such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver ☐

Semi-routine manual and service occupations
such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant ☐

Routine manual and service occupations
such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff ☐

Middle or junior managers
such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager – publican ☐

Traditional professional occupations
such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer ☐

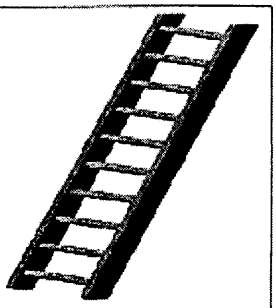
Please read **circle one number** that best describes how much each statement applied to you **during the past month**, including today.

	Have not worked in the past month	Not at all	A little	A fair amount	Much	Very much
I have difficulty talking to the people who work with me about the cancer.	☐	0	1	2	3	4
I have difficulty telling my employer that I cannot do something because of my illness.	☐	0	1	2	3	4
I have difficulty asking for time off from work for medical treatments.	☐	0	1	2	3	4
I have difficulty talking to my boss about the cancer	☐	0	1	2	3	4
I am worried about being fired.	☐	0	1	2	3	4

Think of this ladder as representing where people stand in the UK.

At the top of the ladder are the people who are the best off, those with the most money, most education and most respected jobs. Those at the bottom are the people who are worst off with the least money, least education and the least respected jobs or no job. The higher up you are on the ladder, the closer you are to the people at the top, the lower you are the closer you are to the people at the bottom.

Please place a large 'X' on the rung where you think you stand at this time in your life relative to other people in the UK



THE FOLLOWING SECTION ASKS ABOUT HOW YOU HAVE BEEN FEELING RECENTLY

Tick the box which best describes how often you felt or behaved this way in **the past week.**

	Rarely, none of the time (less than one day)	Some or little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4days)	Most or all of the time (5-7 days)
I was bothered by things that don't usually bother me.	☐	☐	☐	☐
I did not feel like eating: my appetite was poor.	☐	☐	☐	☐
I felt that I could not shake off the blues even with help from my family or friends.	☐	☐	☐	☐
I had trouble keeping my mind on what I was doing.	☐	☐	☐	☐
I felt depressed.	☐	☐	☐	☐
I felt that everything I did was an effort.	☐	☐	☐	☐
I thought my life had been a failure.	☐	☐	☐	☐
I felt tearful.	☐	☐	☐	☐
My sleep was restless.	☐	☐	☐	☐
I was happy.	☐	☐	☐	☐
I talked less than usual.	☐	☐	☐	☐
I felt lonely.	☐	☐	☐	☐
People were unfriendly.	☐	☐	☐	☐
I enjoyed life.	☐	☐	☐	☐
I had crying spells.	☐	☐	☐	☐
I felt sad.	☐	☐	☐	☐
I felt that people disliked me.	☐	☐	☐	☐
I could not get 'going'.	☐	☐	☐	☐

Please mark one box for each statement to show how you have usually felt over the past week:				
Worrying thoughts go through my mind:	A great deal of the time ☐	A lot of the time ☐	From time to time but not too often ☐	Only occasionally ☐
I get a sort of frightened feeling as if something awful is about to happen:	Very definitely and quite badly ☐	Yes, but not too badly ☐	A little, but it doesn't worry me ☐	Not at all ☐
I feel restless as if I have to be on the move:	Very much indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I get sudden feelings of panic:	Very often indeed ☐	Quite often ☐	Not very often ☐	Not at all ☐
I can sit at ease and feel relaxed:	Definitely ☐	Usually ☐	Not often ☐	Not at all ☐
I get a sort of frightened feeling like 'butterflies' in the stomach:	Very often ☐	Quite often ☐	Occasionally ☐	Not at all ☐
I feel tense or wound up:	Most of the time ☐	A lot of the time ☐	From time to time, occasionally ☐	Not at all ☐

THIS SECTION ASKS ABOUT THE SUPPORT YOU RECEIVE FROM THE OTHER PEOPLE

Please circle one response to indicate how much you agree with each statement.	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
There is a special person who is around when I am in need.	1	2	3	4	5
There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5
My family really tries to help me.	1	2	3	4	5
I get the emotional help and support I need from my family.	1	2	3	4	5
I have a special person who is a real source of comfort to me.	1	2	3	4	5
My friends really try to help me.	1	2	3	4	5
I can count on my friends when things go wrong.	1	2	3	4	5
I can talk about my problems with my family.	1	2	3	4	5
I have friends with whom I can share my joys and sorrows.	1	2	3	4	5
There is a special person in my life who cares about my feelings.	1	2	3	4	5
My family is willing to help me make decisions.	1	2	3	4	5
I can talk about my problems with my friends.	1	2	3	4	5

HAS YOUR ILLNESS AFFECTED YOUR EVERYDAY LIFE?

Please read each question carefully and tick the response that best describes your answer. Please tick the 'no difficulty' box if a question does not apply to you.

During the past month:	No difficulty	A little	Quite a bit	Very much
Have you had any difficulty in maintaining your independence?	☐	☐	☐	☐
Have you had any difficulty in carrying out your domestic chores? (e.g. cleaning, gardening, cooking, shopping)	☐	☐	☐	☐
Have you had any difficulty with managing your own personal care?	☐	☐	☐	☐
Have you had any difficulty with looking after those who depend on you? e.g. children, dependent adults, pets)	☐	☐	☐	☐
Have any of those close to you (e.g. partner, children, parents) had any difficulty with the support available to them?	☐	☐	☐	☐
Have you had any difficulties with benefits? (e.g. statutory sick pay, attendance allowance, disability living allowance)	☐	☐	☐	☐
Have you had any financial difficulties?	☐	☐	☐	☐
Have you had any difficulty with financial services? (e.g. loans, mortgages, pensions, insurance)	☐	☐	☐	☐
Have you had any difficulty with your work? (or education if you are a student)	☐	☐	☐	☐
Have you had any difficulty with planning for your own or your family's future? (e.g. care of dependents, legal issues, business affairs)	☐	☐	☐	☐
Have you had any difficulty with communicating with those close to you? (e.g. partner, children, parents)	☐	☐	☐	☐
Have you had any difficulty with communicating with others? (e.g. friends, neighbours, colleagues, dates)	☐	☐	☐	☐
Have you had any difficulty concerning sexual matters?	☐	☐	☐	☐
Have you had any difficulty concerning plans to have a family?	☐	☐	☐	☐
Have you had any difficulty concerning your appearance or body image?	☐	☐	☐	☐
Have you felt isolated?	☐	☐	☐	☐
Have you had any difficulty with getting around? (e.g. transport, car parking, your mobility)	☐	☐	☐	☐
Have you had any difficulty with where you live? (e.g. space, access, damp, heating, neighbours, security)	☐	☐	☐	☐
Have you had any difficulty in carrying out your recreational activities? (e.g. hobbies, pastimes, social pursuits)	☐	☐	☐	☐
Have you had any difficulty with your plans to travel or take a holiday?	☐	☐	☐	☐
Have you had any difficulty with any other area of your everyday life?	☐	☐	☐	☐

Please give details.....

THESE ARE QUESTIONS ABOUT DIFFERENT WAYS OF COPING WITH YOUR ILLNESS

There are many ways to deal with problems, people deal with things in different ways, please try to think about what you have been doing. Tick one box for each item and make your answers as true for you as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
I've been turning to work or other activities to take my mind off things.	☐	☐	☐	☐
I've been concentrating my efforts on doing something about the situation I'm in.	☐	☐	☐	☐
I've been saying to myself "this isn't real".	☐	☐	☐	☐
I've been using alcohol or other drugs to make me feel better.	☐	☐	☐	☐
I've been giving up trying to deal with it.	☐	☐	☐	☐
I've been taking action to try to make the situation better.	☐	☐	☐	☐
I've been refusing to believe that it has happened.	☐	☐	☐	☐
I've been saying things to let my unpleasant feelings escape.	☐	☐	☐	☐
I've been blaming myself for things that happened.	☐	☐	☐	☐
I've been trying to see it in a different light, to make it seem more positive.	☐	☐	☐	☐
I've been criticising myself.	☐	☐	☐	☐
I've been trying to come up with a strategy about what to do.	☐	☐	☐	☐
I've been giving up the attempt to cope.	☐	☐	☐	☐
I've been looking for something good in what is happening.	☐	☐	☐	☐
I've been making jokes about it.	☐	☐	☐	☐
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.	☐	☐	☐	☐
I've been accepting the reality of the fact that it has happened.	☐	☐	☐	☐
I've been expressing my negative feelings.	☐	☐	☐	☐
I've been praying or meditating.	☐	☐	☐	☐
I've been trying to find comfort in my religion and spiritual beliefs.	☐	☐	☐	☐
I've been learning to live with it.	☐	☐	☐	☐
I've been thinking hard about what steps to take.	☐	☐	☐	☐
I've been using alcohol or drugs to help me get through it.	☐	☐	☐	☐
I've been making fun of the situation.	☐	☐	☐	☐

SOME QUESTIONS ABOUT THE WAY YOU THINK AND FEEL ABOUT CANCER NOW

These questions ask about how you think and feel about cancer now. Please circle the number that best describes your response:

	Not at all		Somewhat				Definitely yes
Would you describe this illness as harmful?	0	1	2	3	4	5	6
Would you describe this illness as threatening?	0	1	2	3	4	5	6
Would you describe this illness as a loss?	0	1	2	3	4	5	6
Would you describe this illness as a challenge?	0	1	2	3	4	5	6
Would you rate the experience of this illness as stressful or worrying?	0	1	2	3	4	5	6
Do you feel you have the energy and stamina to get through this?	0	1	2	3	4	5	6
Are you pleased with your outlook on things?	0	1	2	3	4	5	6
Are you pleased with the way you are handling things?	0	1	2	3	4	5	6

PEOPLE WHO HAVE HAD CANCER SOMETIMES FEEL THAT IT HAS MADE POSITIVE CONTRIBUTIONS TO THEIR LIVES, AS WELL AS CAUSING PROBLEMS. IS THIS TRUE FOR YOU?

Indicate how much you agree with each of the following, using these response options.

Having had cancer ...	Not at all	A Little	Moderately	Quite a bit	Extremely
has led me to be more accepting of things.	☐	☐	☐	☐	☐
has taught me how to adjust to things I cannot change.	☐	☐	☐	☐	☐
has helped me take things as they come.	☐	☐	☐	☐	☐
has taught me that everyone has a purpose in life.	☐	☐	☐	☐	☐
has shown me that all people need to be loved.	☐	☐	☐	☐	☐
has made me more aware and concerned for the future of all human beings.	☐	☐	☐	☐	☐
has taught me to be patient.	☐	☐	☐	☐	☐
has led me to deal better with stress and problems.	☐	☐	☐	☐	☐
has contributed to my overall emotional and spiritual growth.	☐	☐	☐	☐	☐
has helped me become more focused on priorities, with a deeper sense of purpose in life	☐	☐	☐	☐	☐
has helped me become a stronger person, more able to cope effectively with future life challenges.	☐	☐	☐	☐	☐

SOME QUESTIONS ABOUT YOU AND YOUR FAMILY

These statements deal with **discussion of your disease with your partner and/or your children**. Please indicate for every statement whether you agree or disagree with it.

	Strongly agree	Agree	Disagree	Strongly disagree
I talk as little as possible about my illness because I don't want to make my family uneasy.	☐	☐	☐	☐
If I talk about my illness, others gloss over it.	☐	☐	☐	☐
My family always wants to hear from me that I am doing well.	☐	☐	☐	☐
Talking about my emotions related to my illness upsets my family.	☐	☐	☐	☐
I am mostly the one who starts a conversation in the family about my disease.	☐	☐	☐	☐

If you do not have a partner or children please tick the 'NA' box for these statements.

	Strongly agree	Agree	Disagree	Strongly disagree	NA
My partner doesn't like me to talk about my problems.	☐	☐	☐	☐	☐
My partner often doesn't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐
My children don't like me to talk about my problems.	☐	☐	☐	☐	☐
My children often don't know what to say or to do when I'm feeling down.	☐	☐	☐	☐	☐

THESE QUESTIONS ARE ABOUT SYMPTOMS AND CONCERNS ASSOCIATED WITH BREAST CANCER

Please circle 1 number per line to indicate how true each statement has been for you during the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have been short of breath	0	1	2	3	4
I am self-conscious about the way I dress	0	1	2	3	4
One or both of my arms are swollen or tender	0	1	2	3	4
I feel sexually attractive	0	1	2	3	4
I am bothered by hair loss	0	1	2	3	4
I worry that other members of my family might someday get the same illness I have	0	1	2	3	4
I worry about the effect of stress on my illness	0	1	2	3	4
I am bothered by a change in weight	0	1	2	3	4
I am able to feel like a woman	0	1	2	3	4
I have certain parts of my body where I experience significant pain	0	1	2	3	4

IN WHAT WAYS HAVE YOUR VIEWS ABOUT YOUR ILLNESS CHANGED FROM WHEN YOU WERE FIRST DIAGNOSED TO NOW?

WE ARE VERY INTERESTED IN HEARING YOUR THOUGHTS, SO PLEASE WRITE ANY COMMENTS YOU HAVE IN THE BOX BELOW:

Thank you very much for taking the time to fill in this questionnaire.